

THE ROLE OF RELATIONSHIPS IN THE CHOICES OF OLDER USERS OF CASH FOR CARE IN ENGLAND

Ricardo J. Rodrigues

PhD

University of York

Social Policy and Social Work

OCTOBER 2014

ABSTRACT

This PhD thesis aims to contribute to a better understanding of how older users of long-term care make their choices regarding care; by exploring the nature of the relationships between older users of Direct Payments (DPs) and their carers, and how those relationships influence the choices and experiences (i.e. satisfaction with care) of users.

This thesis used qualitative methods, including in-depth semi-structured interviews with twenty-four older users of DPs across three Local Authorities within greater London, supplemented by documentary reviews and interviews with nine care managers.

The thesis found that relationships have an intrinsic value for many users as an outcome of care. These users mostly chose to employ a Personal Assistant (PA) and went on to develop deep and caring relationships. The choice to employ PAs was also partly motivated by a desire to ensure continuity of care from the same person. Those purchasing care from agencies seemed to attach less weight to the development of a deep caring relationship, and preferred to have more detached relationships with their paid carers. At the same time, a number of PA employers chose not to employ an existing acquaintance in order to keep the care relationship separate from friendship relationships. All users recognised that the relationship with the paid carer could also have an instrumental value, by allowing PA employers greater leeway in the definition of care tasks than users of agency staff. Reciprocal gift exchanges were reported by those hiring PAs, and were perceived by users as an important way of cementing the relationship and allowing users to receive care tailored to their needs and preferences. Reciprocal exchanges were mostly absent from those purchasing care from agencies.

These findings are discussed in relation to rational choice theories underlining user choice policies in England, as well as to the concept of care as an experience good. Findings highlight the potential role of DPs to allow for a better matching of people with different preferences regarding care, as well as the importance of caring relationships and continuity of care as aspects of home care quality.

TABLE OF CONTENTS

Abstract	3
List of Tables	7
List of Figures.....	8
Acknowledgements	9
Author's Declaration	10
Chapter 1 : Introduction	11
1.1 Background.....	11
1.2 Research question and methods.....	12
1.3 Main findings.....	14
1.4 Chapter structure of this thesis	15
Chapter 2 : Review of the theoretical literature on caring and choice in long-term care	16
2.1 Defining caring	18
2.1.1 Caring as a relationship.....	20
2.1.2 The existence of asymmetric relationships and mutual dependencies	23
2.1.3 Motivations for caring.....	25
2.1.4 The derived demand for care.....	29
2.2 Care as an atypical commodity – the rationale for state intervention in long-term care	32
2.2.1 State intervention on the grounds of equity.....	33
2.2.2 Market failures in long-term care	35
2.2.3 Long-term care as a merit want.....	39
2.2.4 Care as a citizenship right	41
2.3 Choice in long-term care	44
2.3.1 Defining the dimensions of choice: who chooses what.....	45
2.3.2 Choice as an instrument in quasi-markets.....	48
2.3.3 Consumerism and choice as an intrinsic good	56
2.4 Conclusions.....	62
Chapter 3 : Review of user choice policies in long-term care in England.....	66
3.1 Institutional consumerism and quasi-markets.....	69
3.2 Delivering choice to users.....	74
3.2.1 Providing agency, cash and an opt-out to users – Direct Payments.....	76
3.2.2 Mainstreaming user choice through Personal Budgets	80
3.3 Critical assessment of choice in England.....	89

3.4 Conclusions.....	92
Chapter 4 : Research question and hypotheses for investigation.....	94
4.1 Research question.....	97
Chapter 5 : Study design and methods.....	100
5.1 Study design, data and methods for data collection.....	101
5.1.1 Methodological justification for the choice of study design.....	101
5.1.2 Study design.....	103
5.1.3 Selection and recruitment of Local Authorities and care managers.....	108
5.1.4 Selection and recruitment of older users of DPs.....	110
5.1.5 Data and methods for data collection.....	114
5.2 Methods for data analysis.....	118
5.2.1 Model for analysis.....	119
5.3 Ethical governance.....	126
Chapter 6 : Findings of the empirical study.....	128
6.1 Direct Payments in the selected Local Authorities.....	131
6.2 The sample of older users of DPs.....	135
6.3 Users' initial choice.....	139
6.3.1 Context leading to the decision to take up DPs.....	139
6.3.2 Factors impacting the choice of employing acquaintances, strangers or purchasing care from agencies.....	144
6.3.3 Search strategies.....	153
6.3.4 Summary of the main issues related to the process of choosing agencies and PAs.....	156
6.4 The relational aspects of care.....	158
6.4.1 Building and defining relationships with paid carers.....	159
6.4.2 Reciprocity.....	170
6.4.3 Boundaries in relationships.....	175
6.4.4 Summary of the main issues related to the relational aspect of caring.....	180
6.5 Defining tasks and their delivery.....	182
6.5.1 Defining timings and schedules.....	182
6.5.2 Defining tasks - or what and how care is delivered.....	188
6.5.3 Summary of the main issues related to setting times and tasks.....	194
6.6 Relational and experience good nature of care in the context of dementia.....	195
6.6.1 Decision leading to DP and choice of deployment.....	196
6.6.2 Relational aspects of care.....	201

6.6.3 Negotiating tasks and their timing	205
6.6.4 Summary of the main issues related to users with dementia	207
6.7 Conclusions.....	208
Chapter 7 : Discussion	213
7.1 Summary of findings	215
7.2. Discussion of findings.....	218
7.2.1 The intrinsic and instrumental value of relationships in caring.....	219
7.2.2 Reciprocity in the context of dependency	222
7.2.3 Relationships, choice and markets	225
7.3 Policy implications derived from the findings	228
7.4 Limitations, strengths and further research.....	230
7.5 Concluding remarks	235
Chapter 8 : Conclusions.....	238
APPENDIX A : Invitation letter to Director of Adult Social Services for Local Authorities	243
APPENDIX B : Invitation package to LA staff to take part in the interviews.....	245
APPENDIX C : Invitation package to DP users to take part in the interviews	251
APPENDIX D : Consent form for LA staff.....	258
APPENDIX E : Consent forms for DP users	260
APPENDIX F : Topic guides for interviews.....	264
LIST OF REFERENCES	270

LIST OF TABLES

Table 2.1 – Delimiting choice	47
Table 3.1 – Typology of user choice mechanisms in long-term care in Europe	67
Table 3.2 – Use and deployment options for Personal Budgets.....	83
Table 3.3 – Different choice mechanisms and dimensions of choice for home care	84
Table 3.4 – Distribution of PBs by type of deployment and user group.....	86
Table 5.1 – Thematic charts and headings for analysis of qualitative data.....	124
Table 6.1 – Summary of information on DPs in the LAs participating in the study.....	132
Table 6.2 – Characteristics of the sample of older DP users – number of interviewees by Local Authority.....	136
Table 6.3 – Characteristics of the sample of older DP users – number of interviewees by typology.....	138

LIST OF FIGURES

Figure 3.1 – Evolution of care hours provided, by type of formal provider organisations	72
Figure 5.1 – Elements of MAXQDA working environment.....	122
Figure 5.2 – Example of excerpt of the thematic matrix “Feelings with carer” in Excel	123

ACKNOWLEDGEMENTS

I would like to express my appreciation to the many people who have been invaluable to the completion of this thesis.

First and foremost, my deepest gratitude goes to both my supervisors, Prof. Caroline Glendinning and Dr. Richard Cookson. I am grateful for their inspiration, thoughtful insights, patience and support, but most of all for pushing me to explore new solutions and to always seek to improve my work. Their example will always stay with me. I am also grateful to Dr. Kate Baxter for her valuable insights into the research at earlier stages. The maturation of ideas and analysis was also greatly aided by the discussions held with colleagues at the Doctoral Workshop of the German ESPAnet Section.

I am also indebted to the three Local Authorities, which agreed to take part in this study and in particular the three Directors of Adult Social Services and members of staff who generously provided their time to supply me with invaluable information and secure the participation of users. I am also thankful to the users of Direct Payments interviewed for this thesis for agreeing to share their experiences for the purpose of this thesis. In conducting the fieldwork for this thesis, I benefited from being temporarily based at the Personal Social Services Research Unit at the London School of Economics, for which I would like to thank Dr. José-Luis Fernández.

I would also like to thank my colleagues at the European Centre for Social Welfare Policy and Research and a number of friends who have been supportive of my endeavour and who have contributed to the completion of this thesis by providing attentive and comforting ears to my ideas, existential doubts and complaints and have been encouraging throughout. Unable as I am to list everyone here, I would like to single out for a special thank you Pieter and Frédérique and especially Eszter and her family.

Finally, I would like to mention my family who have been supportive and patient throughout the process. I think particularly of my parents, António and Irma, and of Andrea and Joana. Their love made all this possible and I hope this thesis makes them all proud.

AUTHOR'S DECLARATION

I declare that the work presented in this thesis is entirely my own and has not been submitted for examination at this or any other institution for another award.

Parts of Chapters 4, 5 and 6 appear in Rodrigues R. and Glendinning, C. (2014) Choice, Competition and Care – Developments in English Social Care and the Impacts on Providers and Older Users of Home Care Services, *Social Policy & Administration*, [Early view]

DOI: 10.1111/spol.12099

The work presented here, whilst only slightly overlapping with the co-authored work above, is the sole work of the author. Nonetheless, the contribution of Prof. Caroline Glendinning to develop ideas and analysis is hereby acknowledged.

Chapter 1 : INTRODUCTION

1.1 BACKGROUND

The longevity gains observed in high income countries in the past decades bear witness to the improved health experienced by the cohorts born in the second half of the 20th century. The flipside of this remarkable progress in life expectancy is that more people are now confronted with the risk of needing help to perform basic activities that are part of their daily life. Recent data from the Office of National Statistics (2014b) for 2010-2012 places average life expectancy for 65 year old women in England at 21.1 years, of which 12.2 years (57.8% of the average life expectancy at the age of 65) will be spent with some kind of disability. For men the figures are respectively 18.6 and 9.8 years (52.7% of the average life expectancy at the age of 65). However demographic ageing has not only taken place at the top of the age pyramid. Fertility rates have also fallen below replacement levels, which means that in the medium to long-run there might be less people of working age available to care for an increasing number of older people. The possibility of having a diminishing ratio of carers to those in need of care is not triggered by demographics alone, at least not on the supply side. Unpaid care provided in the household has been predominantly carried out by women of working age (Rodrigues et al. 2014). However, societal changes, such as the increased labour market participation of women, or a higher share of the population living alone in old-age, suggest that women may no longer provide care to the same extent that they once did.

In turn, these developments have raised concerns about the need for welfare states to devote increasing resources to long-term care, on top of those required to fund pensions or health care for an ageing population. A recent projection on long-term care costs in England estimates that public expenditure on long-term care for older people could double in nominal terms over a 20 year period, from approximately 12 billion pounds in 2010 to 25.5 billion pounds in 2030 (although in percentage of GDP the increase would be smaller: from around 1% of GDP to 1.3% of GDP) (Hancock et al. 2013). This projection does account for possible policy changes, liable to be introduced to address current unmet needs in the English long-term care system. According to another projection (Fernández & Forder 2011), increased generosity could otherwise triple public expenditure in a 20 year span.

As a result, the issue of long-term care has slowly but steadily attracted more attention from researchers and policy-makers - the limelight has come to shine on issues such as getting the most for the public resources invested. At the same time, the cohorts now experiencing the

need for long-term care have lived their adult lives exposed to and embracing the values of a consumerist society. In the latter, consumers are sovereign and empowered to choose the goods and services that best fit their needs and suppliers are responsive to the changing preferences of consumers. In terms of long-term care, this means future potential users that are probably *less* accommodating of lower quality standards, and *less* willing to accept a paternalistic stance from the welfare state in which professionals decide for them.

It is against this backdrop that the introduction of user choice and competition in long-term care in England, as well as in other countries in Europe, can be framed. Introducing market forces in a sector traditionally dominated by public providers could be seen as the attempt to use the high-powered incentives of the market to increase efficiency. In turn, extending the consumerist values of choice to long-term care could be viewed as a natural response to the wishes of older people turned consumers of care.

When the *1990 National Health Service (NHS) and Community Care Act* came into effect in 1993, this marked the introduction of user choice and competition within publicly funded long-term care provided at home in England. After more than twenty years, the issue of user choice in long-term care continues to be high on the policy agenda and in recent years several changes have been witnessed. One of the key changes has been the introduction of Personal Budgets (PBs) and the possibility for users to take the benefit as a Direct Payment (DP) in cash to be spent on services purchased from home care agencies or on hired Personal Assistants. The concept underlying these reforms, and indeed user choice as a whole, has been that of the user as a consumer of care, i.e. as the one making the decisions about care that best suits his or her needs and preferences. Despite all the research conducted in England about older users of long-term care living in their own homes, there is still a gap in knowledge about their decision making process, particularly for those that in principle one might expect more closely to resemble consumers: older users who take their PBs as a DP in cash.

1.2 RESEARCH QUESTION AND METHODS

In order to understand choices made by older users of long-term care, this thesis argues that it is first necessary to define and understand the disputed concept of care. A great deal of theoretical literature on which user choice has been anchored more or less explicitly considers care just like any other commodity that can be traded in a marketplace - and yet care is actually a value-laden concept. This thesis is particularly interested in the concept of care as a relationship. This concept is particularly salient in long-term care as the user is not

only a passive receiver of services, but also a co-producer of care (i.e. care delivery and satisfaction with care depends on the user). The concept of care as a relationship has been theorised in the sociology literature, and even has some partial theoretical counterparts in the economic theory literature (e.g. experience goods), but has not yet received much empirical attention. In order to bridge this gap, this thesis examines this relationship aspect empirically, using older users of DPs in England as a case study. This thesis aims to bridge this gap by contributing to a better understanding of how older users of long-term care make their decisions regarding care, in particular how the relational and co-production aspects of care affect the choices of older people and their experience of care. The main research question this thesis seeks to address is:

How and why are users' experiences with care affected by choosing to hire a personal carer rather than to acquire services from a formal provider?

Drawing on the concept of care as a relationship, it is conjectured that the decision to hire a personal carer (or paying informal carers) instead of purchasing care from a formal provider can impact user satisfaction in two ways:

- Hiring a personal carer or paying informal carers allows users to choose *from whom* to receive care. This should matter to the user if the relational aspects of long-term care are salient, since it would allow the user to build on or establish a relationship with the paid carer – hypothesis 1.
- Having greater command over the choice of the carer could also increase the leeway that user has in defining *what, when* and *how* care is provided; thereby enhancing the user's ability to shape care to his/her needs and preferences – hypothesis 2.

In order to better understand issues around relationships, qualitative research methods were employed, namely in-depth semi-structured interviews carried out between March and May 2013 with twenty-four older DP users across three Local Authorities in the Greater London area. These interviews focused on the users' perceptions of their own decision-making processes in the use of DPs. The contents of these interviews were then analysed using Framework Analysis (Ritchie & Lewis 2003) with the help of the MAXQDA software for qualitative data analysis. Interviews with older DP users made up the main part of the empirical study of this thesis, but they were preceded and supplemented by a study on the institutional context of choice by older users of DPs across the three Local Authorities, which comprised documentary reviews and nine interviews with care managers.

1.3 MAIN FINDINGS

The research carried out has produced four main findings on older DP users:

Firstly, the findings of this thesis seem to confirm that relationships play an important role in the initial decisions on how to deploy DPs for many older users of DPs; albeit this role was different for those employing PAs and those purchasing care from agencies. Two examples illustrate this. On the one hand, users who valued relational aspects of care tended to use their DPs to employ PAs. On the other hand, some users explicitly sought not to employ acquaintances as their PAs so as to keep employment relationships and kinships or friendships separate.

Secondly, relationships can also influence the experience of receiving care. On the one hand, relationships could have an intrinsic value as an outcome of care. On the other hand, relationships also had an instrumental value by contributing to enhance the user's ability to determine how and when care was delivered. Perhaps the best example of this instrumental value of relationships was how establishing a bond with the carer ensured that users with dementia cooperated in the delivery of care.

Thirdly, relationships in care were very different depending on the groups of users. Users that had employed a PA reported having much closer relationships with their carers. In contrast, users who received care from home care agencies reported much more detached relationships with agency carers and stated strong preferences for not having close relationships with their paid carers.

Finally, reciprocity is a defining characteristic of caring relationships. Closer relationships with PAs often involved non-monetised gift exchanges between users and paid carers. These reciprocal exchanges were absent from the more professional-like relationships with agency carers where opportunities for reciprocity were more limited due to agency rules that prevented gift exchanges. These reciprocal exchanges not only cemented close relationships, they also helped users to better tailor care to their needs and preferences.

Still regarding these reciprocal exchanges, and although not directly a finding *per se*, this thesis raises the hypothesis that reciprocity can be understood as a way to cement relationships (i.e. to reduce carer turnover) and to spur the provision of caring feelings and emotional support by appealing to moral norms rather than financial incentives.

In conclusion, the findings of this thesis corroborate that relationships can influence the choices of older DP users, albeit in different ways, as well as the experience of care. This relational component of care further strengthens the experience good nature of long-term care and gives credence to the concept of user as a co-producer of care.

1.4 CHAPTER STRUCTURE OF THIS THESIS

This thesis is organised as follows. Chapter 2 presents a theoretical review of the literature pertaining to the concept of caring and the issues around state intervention and user choice in long-term care. This chapter brings together concepts and rationales from different theoretical streams – ranging from feminist and disability scholarship to consumerism and rational choice – that when taken together are important for the discussion of user choice policies in long-term care. Chapter 3 provides a more empirical-based review of the implementation of user choice policies and quasi-markets in long-term care in England. This chapter covers a wide time period, from well before the 1990 *National Health Service (NHS) and Community Care Act* to the present day, and provides not only an overview of the measures taken and their underlying arguments, but also a critical appraisal of its effects. This chapter also identifies some of the gaps in knowledge that this thesis attempts to bridge. Chapter 4 focuses on the research question, while Chapter 5 details the research design, data and methods employed to carry out the empirical study of this thesis. Chapter 5 also discusses the rationale for choosing qualitative research methods to carry out this research. It then proceeds to provide a detailed account of the fieldwork and analysis carried out.

Chapter 6 details the empirical findings of this thesis. This includes a description of the most relevant characteristics of the Local Authorities and older DP users that participated in this study and an analysis of the narratives of users, including relevant sub-groups of the sample. Chapter 7 provides a discussion of the main findings of this thesis. This includes placing the findings in the broader context of the theories and concepts reviewed in Chapter 2, confronting the findings of this thesis with previous empirical studies, discussing the possible policy implications arising from the findings and debating the strengths and limitations of this thesis, as well as future research possibilities. Finally, Chapter 8 concludes with a summary of the key findings of this thesis and how they contribute to advance the theoretical and empirical knowledge on user choice in long-term care.

Chapter 2 : REVIEW OF THE THEORETICAL LITERATURE ON CARING AND CHOICE IN LONG-TERM CARE

The present chapter aims to provide an overview and critical appraisal of the existing literature on the nature of *long-term care*, or more simply *care*¹, as a concept and commodity, its allocation through market mechanisms and the use of choice by those in need of care. In doing so, it will seek to integrate contributions from several disciplines in order to provide answers or at least discuss possibilities for the questions posed above. For the purpose of this thesis, long-term care is defined as care for people in need of support to carry out denominated activities of daily living (ADLs) (e.g. bathing, dressing, using the toilet) and instrumental activities of daily living (IADLs) (e.g. cooking, managing medication, shopping) for a prolonged period of time. This definition includes not only ADLs, as is the case with the definition of long-term care used by the OECD (cf. Colombo et al. 2011, p.39), but also IADLs as the latter are important for independent living.

Demographic ageing and societal changes have increased concerns about how to provide and fund care needs of frail older people in light of tighter welfare budgets. This has brought to the forefront concerns about how to increase the efficiency of provision of care to frail older people – also denominated *long-term care*. In this context, the introduction of market-like mechanisms to provide care to frail older people became a seemingly natural response, since one of the main tenets of economic theory is that contestable markets are the most efficient way to produce and allocate services. Creating a market-like arrangement for the provision (i.e. production and delivery) of care called for the introduction of competition and choice (Le Grand 1991a; Bartlett & Le Grand 1993) and these became not only the buzzwords but also mainstays of the policy reforms introduced in long-term care all over Europe (Taylor-Gooby 1998; Pavolini & Ranci 2008).

Despite the growing interest that care for older people has come to merit and the proliferation of market-like arrangements in this area, the “economics of long-term care” has remained a somewhat fragmented and under-researched theme within mainstream economics. Is long-term care a typical commodity liable to be bought and sold on the market?

¹ The terms *long-term care* and *care* will be used interchangeably as synonyms throughout the thesis.

What characteristics does it possess that could somehow distinguish it from other commodities including health care? What drives demand and supply of long-term care?

These are just some of the questions for which it is difficult to find answers in the mainstream literature in economics. Yet as the recent reforms have emphasised the introduction of market mechanisms or market provision of long-term care, these questions should merit a greater reflection than they have received so far. As far back as 1963 in a seminal article titled *Uncertainty and the Welfare Economics of Medical Care*, Arrow was able to demonstrate the specific characteristics of health care that set it apart from other commodities. In what regards long-term care, a similar framework of analysis is still lacking or is patchy at best, with the exception of Knapp's rather comprehensive work *The Economics of Social Care*, but which dates back to 1984. It is not that the issue of care as a concept or commodity has not deserved interest - on the contrary it has been a hotly debated issue (see for example Jochimsen 2003; Kröger 2009). The particularities of caring for dependent older people have been brought forward by those fearing the excessive commodification of care or by the feminist literature (see for example Dorman et al. 1996). This discussion, however, has not been translated into a positive theory about how the particularities of care could affect the functioning of a care market. Yet, in order to understand choices made by users of long-term care – the main aim of this thesis – it is important to understand the characteristics of long-term care, for these affect how people make their choices and ultimately how markets work (Roth 2007).

This chapter is organised as follows. The first section reviews the multiple definitions and debates around the concept of caring - and whether care is different from other commodities traded in markets. This section reviews the arguments of the feminist and disability critique as well as the discussion around the motivations for caring and the issue of care as a derived demand. The second section looks at the reasons brought forward to justify state intervention in the provision of long-term care and how these are impacted by the specificities of care as a commodity. Most of the arguments reviewed in this section are firmly anchored in mainstream economics and revolve around issues such as equity or market failures. This section also includes contributions from other currents of thought that are important to understand state intervention in long-term care. Taken together, these arguments contribute to understanding the limits to the use of competition in long-term care and why markets of care differ from conventional markets. The third section reviews the arguments both in favour and against the introduction of user choice in long-term care – again not just from the point of view of mainstream economics, but also from other disciplines. Finally, the fourth

section provides a brief conclusion of the salience of the different theories for the discussion around long-term care and choice.

2.1 DEFINING CARING

Unlike medical care (understood here as care provided by general practitioners, secondary and acute care) the focus of long-term care is not on curing but caring, which can take place during an extended period of time. Furthermore, in the majority of cases, long-term care will not bring about a complete and absolute reversal of the state of dependency. This is not to say that the decline is irreversible or that no improvement is possible² – thus the room for rehabilitation as one of the services included in long-term care. In order to be able to conceptualise the extent to which market mechanisms or market provision can impact long-term care, it is useful to first take a step back and review the concept of caring and how it might relate to the issues of providing care through the market. Himmelweit's (2007, p.583) critique that "An economic analysis that includes caring must therefore take account of the ways in which the production, allocation and distribution of care do not conform to the assumptions that economists usually make" is very much to the point here.

The concept of caring has been a prime subject of interest for the feminist scholarship, as part of its critique of the male-centeredness of mainstream economics and welfare policy (Fine & Glendinning 2005). By discussing care, feminist scholars have sought to uncloak the veil of invisibility that had very often covered this subject - an activity traditionally performed by women, within the household and generally without pay. The concept of care as discussed by the feminist scholarship came to serve a dual purpose: on the one hand descriptive, as applied to the existing reality; and on the other hand, normative, as linked to a given vision or ideal construct, against which reality is sometimes compared with (Fine 2007).

The feminist scholarship has conceptualised caring along the distinction of caring as a motivation or feeling of concern for others, and caring as an action or task. These terms are encapsulated in the initial conceptual distinction made by Graham (1983) of *caring about* and *caring for*. As Fine (2007) notes, caring as a feeling of concern and caring as an action have often been addressed separately in the literature. For example, the *ethics of care* has started

² This is one of the reasons why the assessment of outcomes in long-term care is quite different from health care, for while in the latter it is possible to devise crude measures of outcome based on morbidity or mortality of patients, in the former these measures lose some of their applicability as complete recuperation may not be attainable.

from *caring about* as a particular disposition to go on and construct a series of values based on the concern for personal relationships that should steer moral action (for example Gilligan 1993; Tronto 1993). Others have elected to emphasise the policy implications, notably for carers, that stem from *caring for*.

Furthermore, the phenomenon of care takes place in different contexts and regarding different persons. Jochimsen (2003) for example, refers to three types of caring activities that focus on people: *self-care*, referring to care activities performed on his/herself; *caring for kin or friends*, where the person receiving care is able to provide an equivalent return or eventually care for his/herself; and *care for dependents*, where the person receiving care cannot survive without the assistance of the carer. Both Jochimsen (2003) and particularly Bowden (1997) stress that caring entails different things in each of these contexts.

The concept of *caring* is nevertheless one that is far from being consensual. The approach taken by the feminist scholarship for example, by stressing the viewpoint of the carer - and in particular the female carer - as well as focusing on the *burden of care*, has been challenged on several grounds. Fine and Glendinning (2005) for example contest the extent to which this *female carer-centred* approach has neglected the role of men as carers particularly for their frail or disabled spouses. They also question how it will be able to hold in the face of demographic changes that have witnessed an increase in male life expectancy in old-age.

These two authors also echo another criticism regarding the feminist scholarship's approach to care: that it is built around a dichotomy between the carer and the dependent person. This dichotomy fails to recognise the dual role of many frail older or disabled people that both receive and provide care as parents, spouses or grandparents. It is furthermore conducing to portrait those in need of care in a passive and burdensome role. This critique however, is not only addressed to the feminist scholarship but to the wider treatment of concepts such as independence and autonomy. Sevenhuijen (1998) for example, is among those to note that personhood has traditionally been linked with autonomy and independence, which has had the effect of marginalising dependency as something to be avoided or reversed.

Drawing from a wide body of literature (see Tronto 1993; Leira 1994; Folbre 1995; Nelson 1999; Himmelweit 1999; Daly & Lewis 2000; Folbre & Nelson 2000; Jochimsen 2003; England 2005; Fine 2007; Himmelweit 2007; Folbre 2008; Kröger 2009) it is possible to attempt a synthesis of the complex concept of caring for frail older people around some more consensual dimensions and discuss how they might impact care as a commodity. The analysis of the concept of caring will also include salient links to other areas outside the feminist

literature. Therefore, in analysing how the concept of caring may impact the provision of care through the market, it is also important to bear in mind two other characteristics of care. Namely, that care is what in economics is termed as a derived demand (Baxter et al. 2011), arising not just from the preferences or whims of people but also from need (Hodgson 2008). Care as a derived demand entails that people do not seek care for its own sake but to benefit from its outcomes (Hurley 2000), whilst the distinction between demand or want and need has significant implications in terms of the ability of the market to allocate care to those that most require it.

Therefore, the dimensions around which the discussion will be centred are: (1) caring as a relationship, (2) subject to asymmetries, and marked by mutual dependencies of individuals taking part in the caring process, (3) where motivation is an essential aspect to understand care, and finally (4) care as a derived demand arising from need rather than want. The following sections deal with each of these dimensions separately.

2.1.1 CARING AS A RELATIONSHIP

The importance of caring as a relationship seems to be a common topic in the literature on the subject, from the earlier notions of the ethics of care, constructed precisely around the concern with human relationships (Gilligan 1993), to the more recent strands of the feminist and disability scholarship. Thus, for Himmelweit (1999, p.30), caring is the development of a relationship for it encompasses more than just physical tasks to include emotional support, otherwise it would be no different from other domestic work, for “it matters who is doing what for whom”. Jochimsen (2003, p.3) puts the emphasis of caring as involving the establishment of a relationship forged over time between the carer and the person cared for: “to care is to relate”. It therefore involves an aspect of continuity that is absent in acute care, or even in care provided by general practitioners (GP). The relational dimension of care is also central to the analysis of caring as a power structure undertaken by Kittay (1999; cited by Fine 2007, p.68ff).

The fact that caring has this relational dimension carries with it important implications also from the point of view of mainstream economics: 1) caring becomes an example of an *experience good*, whose quality can only be correctly assessed by users while experiencing it; 2) furthermore, quality is not only remarkably difficult to assess *ex ante*, but it crucially depends on the person cared for; 3) it imposes limits to productivity gains that do not compromise quality; and finally, 4) caring as a relationship implies that carers may develop

feelings of attachment and thus exhibit what the literature terms as *endogenous preferences*. Each of these implications is examined below.

For most commodities consumers are able to judge the quality of a commodity prior to purchasing it – these are termed *search goods*. However, there are several commodities for which quality can only be gauged after consuming it – *experience goods* (Nelson 1970). A classic example is labour, with both employer and employee only able to correctly assess the quality of their match after the hiring process has taken place. Folbre and Nelson (2000) describe an ideal caring relationship as one where the person receiving care is able to feel emotionally connected and supported, nurtured and valued as an individual. These feelings depend greatly on the rapport established with the carer which the person receiving care can only be sure of experiencing once the caring process has taken place. To a great extent the *experience good* nature of caring stems also from the fact that the person receiving care is also taking part in the production process, which is the ensuing argument presented by Davies and Knapp (1981) and Baldock (1997).

By defining care as a relationship, this means that caring requires the involvement, or at least the passive consent, of the person receiving care for the process to even take place. Therefore, quality and satisfaction derived from the caring relationship become very much dependent on the person receiving care (Baldock 1997). The reactions and subjective values of the person receiving care not only constrain the care that is provided, but also greatly influence the degree of satisfaction that the person receiving care is able to experience. The quality of social relations thus becomes an outcome of care and a quality indicator, but one that is likely to be difficult to gauge or specify in a contract since it is intangible (Eika 2009, p.115). Moreover, it becomes much more difficult to isolate which variables may be associated with certain outcomes, for these may well be endogenous. If those receiving care have very strong preferences for remaining at home together with their families (who very often will be simultaneously acting as carers), this may be the decisive factor explaining why certain people will remain at home despite deteriorating health conditions or relative unavailability of home care services.

Baumol (1967) once presented the example of the performing arts as an activity where the amount and quality of the labour employed was paramount in achieving quality and where therefore the scope for continuous productivity gains was limited. In his example, a piece of classical music written for a quintet needs a certain amount of man hours to be performed and one cannot conceive of maintaining quality if there are four musicians rather than five, unless they were to play a different piece. Himmelweit (2007) and Fine (2007) draw a

parallel between Baumol's example and caring. By relying on human interaction to such a great extent, there is a physical limit to the number of persons that the same carer can attend to. Productivity gains are therefore limited, since reducing the time needed to deliver care, for example, by *Taylorising* care, can only be possible at the expense of quality. This is not to say that productivity gains are barred from occurring altogether. For example, there might be scope for time savings in travelling or other ancillary tasks that would free time for caring tasks, in a similar way that plane travel allows for a greater number of performances in Baumol's quintet example. But ultimately there are only so many persons one carer can forge a caring relationship with and as long-term care is a labour intensive sector replacing labour with capital is not really feasible³. The outcome is akin to the "cost disease" that Baumol and Bowen (1965) described again in reference to the arts. As productivity gains in the care sector would fall short of the rest of the economy, the relative price of professional care would increase because wage growth in this sector would likely have to increase at a higher rate than productivity, for otherwise formal providers (i.e. agencies or care homes) would not be able to attract workers. More importantly, caring as a relationship implies that efficiency gains brought by market provision of care and measured in a narrow sense (i.e. without considering quality) may actually be limited or, if taken too far, prove detrimental to the quality of caring.

Persons receiving care as well as carers both seem to value the development of long-term relationships (Glendinning, Halliwell, et al. 2000). For carers however this may result in the development of a sense of attachment with the person they care for, i.e. their commitment to care may increase with provision of care. This is what the literature refers to as *endogenous preferences* (England & Folbre 2003; England 2005). This means that carers may face higher barriers to exit once a caring relationship has been established. They may also have a reduced bargaining power – for example, they may be reluctant to undertake a labour strike as this may be harmful to the wellbeing of those they care for – and consequently be more vulnerable to exploitation, even by the state if public authorities assume that they can cut down on public support for carers as carers will not abandon what they perceive as their caring responsibilities (England 2005).

³ Another consequence of this is brought forward by both Baumol (1967, p.423) and Himmelweit (1999, p.586), whereby these bounded productivity gains inherent to the characteristics of activities such as caring (or urban administration in Baumol's example) may be misread as inefficiencies and be used as a further argument for privatisation.

2.1.2 THE EXISTENCE OF ASYMMETRIC RELATIONSHIPS AND MUTUAL DEPENDENCIES

In defining care for dependents, Jochimsen (2003, p.14) refers to “care provided for young children, the frail elderly, the sick and the disabled who cannot survive or function... without steadily caring personal assistance”. For Jochimsen (2003) the inequalities of capability for self-care are the underlying root of the asymmetries that characterise caring for dependents. In turn, Himmelweit (1999) defines caring for a dependent as an asymmetric relationship due to the limited ability of the person receiving care to reciprocate.

According to this view, the asymmetries and dependencies attached to caring for frail older people stem from the differences in the capability of the carer and the person receiving care to perform self-care. For Jochimsen (2003, p.89ff), this “existential dependency” has two very concrete and immediate consequences for the person receiving care: it conditions his/her decision of entry or exit into the caring relationship and makes demand for care inelastic. It therefore contradicts or at the very least questions the notion of the person requiring care as an independent and autonomous consumer operating in the market.

As mentioned above however, defining care around the inexistence of autonomy and (in)ability to reciprocate is firmly contested by the disability literature. Some argue instead that independency should be formulated around the control over the decision-making process and not necessarily over the ability to execute the decisions (Collopy 1995; cited by Fine & Glendinning 2005, p.610). Other authors, such as Kröger (2009), propose a synthesis of the concept of caring that acknowledges its emotional aspects, but also the interdependence inherent to the relationship between the user and the carer. Another alternative view proposed by Fine and Glendinning (2005) is to build on Kittay’s (1999) concept of care as a power relationship, and frame the asymmetries and mutual dependencies as inequalities in power, for example, over the control of resources.

The frail health condition of the person in need of care may preclude effective control over his/her resources, namely pecuniary, thus entailing dependency on the carer or formal provider. An example of this is if access to residential care is conditional on selling one’s own house, whereby the user effectively relinquishes control over financial resources to the state or the formal provider. For Jochimsen (2003), the person in need of care may also be dependent on the carer or third party (the state, or a professional or formal provider acting as the agent) for the determination of needs and preferences. Frailty may prevent the person in need of care from expressing preferences or determining what are his or her needs. The assessment and determination of needs by a third party may also be the result not of lack of

cognitive ability by the person in need of care, but result from the complexity of the diagnose and/or intervention needed – this is usually the case with medical care. It may also arise due to the institutional design of available social support, for example, when determination of need is associated with the benefit of an in-kind or cash transfer from the state.

The asymmetric nature of the caring relationship arising from control over resources may also be to the detriment of the carer or liable to place him/her in a vulnerable situation. Take the case of cash benefits provided to those in need of care as they can be used as “routed wages” (Ungerson 1997), i.e. passed on as a material reward or wage to the carer. Analysed alone, these benefits can constitute an example of an asymmetric relationship where the carer is materially dependent on the person cared for. The institutional context is thus an important variable in determining some of the asymmetries of the caring relationship. Following Fine’s (Fine 2007, p.68ff) account of Kittay’s (1999) work, the carer may also be faced with an unequal material relationship regarding not the person cared for but a third party. This could be the male breadwinner in a household context, or the employer in the case of a paid carer. This dependency on a third party may result from the commitment of the carer to the wellbeing of the person cared for, or stem from notions of lower social status and recognition associated to either the task (caring) or those traditionally undertaking it (women). These asymmetries, however, seem to configure more an interdependent relationship rather than a totally asymmetric relationship and therefore come closer to the vision of care as proposed by authors such as Fine (2007), Fine and Glendinning (2005) and Kröger (2009).

There is however, another important asymmetry or dependency to consider. This relates to motivations or societal and cultural norms regarding who is responsible for providing care. If powerful enough, societal and cultural norms may act as a further deterrent to exit, or condition entry into the caring relationship by the carer. The workings of motivation though are slightly more complex. Caring motivation is a powerful driver in establishing caring relationships, where the person cared for cannot always reciprocate or provide returns. But the advantageous position enjoyed by the carer in the relationship may evolve into a moral obligation of caring, particularly the greater the asymmetry in capabilities (Jochimsen 2003). This can constitute a further and quite effective barrier to exit the relationship by the carer. Jochimsen (2003) draws a parallel with Hirschman’s (1970) loyalty concept applied to consumer and firms. As with the original example of loyal consumers that do not exit the exchange with the firm in the event of a drop in quality (thus allowing time for the firm to correct itself), caring motivations may also inhibit exit, with its attached *moral shame*, in

favour of a continuation and further investment in the caring relationship. While this mechanism may work in favour of assuring continuity, it could also be taken too far and thus explain sacrifice on the part of the carer. In the words of Folbre (2008), the carer could thus become a “prisoner of love”. This moral dimension associated with caring seems quite far from the notion of self-interest central to the *homo economicus* that inhabits the market. Furthermore, engaging in a caring relationship may thus not necessarily be a voluntary decision, certainly not for the person in need of care, but also not for the carer.

2.1.3 MOTIVATIONS FOR CARING

At first glance motivations behind the decision to care should be of prime concern for economists, as after all economics is “A social science that studies individual and group decisions” (Black et al. 2009), as well as for social policy analysts, since “Assumptions concerning human motivation and behaviour are the key to the design of social policy” (Le Grand 1997, p.153). Motivation for caring (involving both paid and unpaid care) has in fact been conceptualised through two different perspectives:

1. Allowing for altruist motivations, as defined by Becker (1976);
2. Assuming that caring is linked to moral motivations that go beyond or even contradict the notions of self-interest or Becker’s (1976) altruism.

Caring for altruistic reasons

Although the term *altruism* is usually meant as a disinterested and selfless concern for the welfare of others, thus implying that one gives without expecting anything in return, the utility-based concept has quite a different meaning. Caring, as modelled by Becker (1976), takes place because the carer’s wellbeing improves with the wellbeing of the person cared for. Therefore the carer is willing to forfeit consumption or leisure in favour of increased consumption by the person receiving care but only to the point where doing so increases the utility of the carer. *Becker-altruism* as defined in this way entails something in return for the carer.

In practical terms Becker-altruism can be modelled in two different ways. Either by assuming interdependent utility functions, whereby the utility of the carer depends positively on the utility function of the person receiving care, or through some sort of reward from the person receiving care, which in the absence of pecuniary or other material retribution can take the form of “psychic income” (Becker 1976, p.175).

Netten and Davies' (1990) model of *social production of welfare* allows for a more nuanced view of caring⁴, but the underlying motivation behind caring for other members of the household remains anchored around the utility-based concept of altruism. In their model, the wellbeing of one household member depends also on the satisfaction that the other members of the same household derive from commodities produced by the former. Although Netten and Davies refer to Sen's (1977; cited by Netten & Davies 1990) notion of *commitment*, they in fact model this concept in the same way as Becker-altruism. Regarding the production of care, for Netten and Davies (1990, p.341 emphasis added) "the motivation for production is to achieve *one's own* and *other's* welfare or utility", while in Sen's (1997, p.93) words "commitment [...] involves choosing an action that yields a lower expected welfare than an available alternative".

Taking Jochimsen's (2003) critique, the issue with the above formulation of caring around Becker-altruistic motivations is that not all caring relationships can be modelled as a result of preferred choice, or built around the expectation of return, which underlies both interdependent utilities and psychic returns. Instead, caring relationships may be regarded as "gifts, as sustained one-way transfers – without assuming even an implicit or deferred exchange pattern" (Jochimsen 2003, p.39). Furthermore, caring relationships may be built around moral obligations, vocation or altruism as it is commonly understood.

Beyond self-interest

One of the most quoted passages from the *Wealth of Nations* describes the self-interested behaviour that underlines neoclassical economic thinking:

It is not from the benevolence of the butcher, the brewer, or the baker that we expect our dinner, but from their regard to their own interest. We address ourselves, not to their humanity but to their self-love, and never talk to them of our own necessities but of their advantages. (Smith 1776, p.13)

However, a number of scholars have questioned not only whether self-interest may correctly describe caring relationships, but also how self-interest could affect caring relationships –

⁴ For example, Netten and Davies build on Becker's (1965) and Lancaster's (1966) notion of the household as a unit of production and consumption of household commodities (caring included), whose demand and ability to produce these commodities depend on the needs of the household members.

namely to what extent it should be the main motivation behind them or how it could affect them (Waerness 1987; Leira 1994; Folbre 1995; Dorman et al. 1996; Folbre & Weisskopf 1998; Himmelweit 1999; Folbre & Nelson 2000; Nelson 1999). The question posed by this literature is: if caring is fully commodified, would this mean that self-interest, the driving force behind exchanges in the market realm, would become the only or main motivation for caring?

Going back to the above mentioned notion of caring as a relationship and as being comprised as both an emotional dimension, *caring about*, as well as a physical one, *caring for*, Himmelweit (1999, p.29) stresses that “A carer will not succeed in delivering good care unless she appears to the person being cared for (the caree) to be motivated by genuine concern over his wellbeing”. In this sense, caring is close to the concept of “emotional labour” (Hochschild 1983; cited by Himmelweit 1999, p.34) as one that requires the management of the carer’s emotions in order to create a particular feeling (such as being nurtured or cared for) for the person receiving care. There are other occupations that qualify as emotional labour, from flight attendants to waiters, but the effectiveness of these tasks do not hinge on the establishment of a relationship, as caring does.

The commodification of emotions or paying to enlist one’s concern could thus render the individual vulnerable to the selfish interests of the carer (Jochimsen 2003, p.34), attract the wrong type of carers, or have a negative impact on the supply of caring (i.e. the feeling of concern) as explored in the *motivation crowding theory* by Frey (1998). The basic rationale of the latter is that extrinsic motivation (such as monetary incentives, or regulations with punishments and mandates) can crowd-out or crowd-in intrinsic motivations (self-fulfilment or vocation) depending on the former being seen as a form of control or acknowledgement⁵. This rationale has obvious links to Titmuss’ (1970) critique of remunerating blood donation – an example of a monetary reward crowding-out a behaviour driven by intrinsic motivations – as well as Le Grand’s (2003) debate over the knightly or knavish nature of those delivering social services⁶. As Folbre (1995, p.75) notes “Sometimes, the motive for engaging in a certain

⁵ However, as England (2005, p.394) stresses, the effect of payments on intrinsic motivations may be dictated by circumstances and in particular by the fact that the empirical studies conducted involve “crossing the highly charged symbolic divide between things done for no money at all versus those done for money”.

⁶ The issue is also not new to the denominated transaction costs economics, for Williamson (1993, pp.480–482) also noted that exchanges that carry with it attitudinal spillovers and attached

activity affects the quality of the service being provided". Thus, as market mechanisms and extrinsic motivations are extended into long-term care, this begs the question: would the market fundamentally change (for the worst) the quality of the caring relationship?

Concomitantly, the commodification of love can also be analysed through the lens of the nuanced role that money can play in transactions. In mainstream economics, employing money as a means of payment does not change the nature of the transaction or the commodity being exchanged (Sandel 2013). In the wake of Titmuss' (1970) above mentioned arguments however, Sandel (2012) and Roth (2007) caution that some commodities have attached strong moral norms. These moral norms may be powerful enough to render cash payments useless in bringing about certain behavioural changes. Although neither Sandel nor Roth mention long-term care in their examples, *paying for love or for concern* could conceivably be considered a non-neutral moral transaction and impact the provision of care.

There is, however, also somewhat of a dichotomy underlying the motivation crowding theory (England 2005) and an implicit romanticised view of caring as a vocation that needs to resist contamination by self-interested motivations in order to maintain its real meaning⁷. Authors such as Nelson and Folbre (2000) contend this view of *either "for love" or "for money"* and propose somewhat of a synthesis of the two as a way to better capture the motivations for caring. Admittedly Nelson and Folbre build their vision with a purpose to vindicate proper compensation for carers, but Nelson (1999, p.46) draws attention to the fact that exchanges taking place in real rather than stylised neoclassical economic markets can best be characterised as "rich and complex social relationships", rather than being driven by self-interested calculus alone. Carers may respond to monetary incentives without that constituting a blatant proof of self-interested behaviour. Indeed, carers must also satisfy their individual needs and/or those of their families, or perceive monetary incentives as recognition for their work – which according to Frey's framework would not be at odds with their intrinsic motivation for caring. Money may also play a more nuanced role in transactions besides the ones mentioned above by Sandel (2012), acting not only as a

non-pecuniary rewards may be seriously disrupted if they were suddenly seen as ordinary transactions taking place in the market domain and subject to market valuation.

⁷ Coming from almost two opposing approaches, Heyes (2005) goes as far as using the vocational underpinning of nursing to build a theoretical model explaining "why a badly paid nurse is a good nurse", while for Held (2002; cited by England 2005) carers should receive adequate pay but be confined to the public or non-profit sector. In his view if caring is otherwise left to the private sector it will eventually demand the complete commodification of the emotional caring component as well.

medium of payment, but also as part of a gift exchange between the carer and person cared for in the context of labour contracts (Akerlof 1982). Furthermore, assuming self-interest to be incompatible with a true and desirable caring relationship would leave the carer vulnerable to situations of extreme self-sacrifice and exploitation – a “prisoner of love”.

Beyond the normative implications attached to Nelson and Folbre’s (2000) arguments, the “love and money perspective”, as England (2005, p.392) coined it, allows for a richer characterisation of caring as a long-term relationship of a personal nature, shaped not only by preferences (akin to neoclassical economics), but also by values and norms (England & Folbre 2003). It is therefore possible to understand care choices as based not only on financial considerations, but also on attitudes and expectations, as Eichler and Pfau-Effinger’s (2009) account of choice and preferences for family care in the context of the German long-term care insurance indicates.

2.1.4 THE DERIVED DEMAND FOR CARE

Beyond the consequences that arise from the particular attributes of caring according to the feminist scholarship, there are two other concepts that are not new to economic thinking, but that have received little reflection regarding long-term care: the concepts of (1) derived demand and (2) need. Both these concepts have been primarily discussed in the context of health care (Hurley 2000; Hodgson 2008; Culyer 2007). Whilst safeguarding the differences between health care and long-term care, it is nonetheless around that discussion that the present section is anchored.

When arguing for the distinctiveness of health care as a commodity, one of the singularities put forward by Hurley (2000, p.68) is that the demand for health care is not associated with the direct satisfaction associated with its consumption. Rather, it is derived from the outcome that it produces: good or improved health. Similarly, demand for long-term care does not arise from the satisfaction that one is likely to get from receiving care and in some circumstances care may even be perceived as a *necessary evil* (certainly when compared to living independently or being in good health). Thus, long-term care is not demanded as an end in itself (Knapp 1984), but as a means to improve or guarantee users’ ability to function and/or their personal autonomy.

Baxter, Glendinning and Greener (2011, p.95) recognise that people’s demand for long-term care “is derived from their need for support”. In doing so, they highlight an even more crucial point regarding the demand for long-term care: it stems from needs rather than wishes,

whims or wants. This has important consequences for applying neoclassic consumer choice theory to long-term care and for consequently portraying it as a standard commodity, not least because it severely limits the possibility for those in need of care to exit the market.

In conventional markets, demand is the revealed preference of consumers: it is a want or represents a shortfall for which consumers are able and willing to pay in order to get the means to satisfy that want or cover the shortfall. Demand for luxury goods, for example, is the expression of want by consumers who are able and willing to pay the market price in order to use luxury goods to obtain status. It is hard to imagine any moral or ethical value attached to the consumption (or lack) of luxury goods. Need, on the other hand, not only refers to a shortfall that can be addressed, but also to one that ought to be addressed (Knapp 1984; Culyer 2007). In the words of Bradshaw (1972), needs therefore have a normative dimension. This argument is also used by Culyer (2007) when distinguishing preferences from needs, when he refers to the fact that the latter have an “ethical weight” attached to its outcome. While his definition referred to health care, it can easily be transferred to long-term care. Thus, long-term care is the mean to achieve physical survival and personal autonomy, which are outcomes that carry with it an “ethical desirability” (Culyer 2007, p.234), unlike, for example, luxury goods. In the case of long-term care, the ethical importance of its outcomes derives from the fact that “since physical survival and personal autonomy are the preconditions for any individual action in any culture, they are the most basic human needs” (Doyal & Gough 1991, p.54). As Knapp (1984, p.19) recognises, need is therefore a concept closer to social demand, i.e. to the price that society is willing to pay to provide the means to address a given shortfall.

Although it would be erroneous to link long-term care needs to health condition alone, it is nonetheless possible to adapt the terms employed by Hodgson (2008) to characterise health care needs as being involuntary, unequally distributed and both heterogeneous and idiosyncratic. The same can be applied to long-term care.

Long-term care needs are involuntary because they result for the most part not from the individual’s actions, nor from circumstances under his/her control. With notable exceptions (e.g. dependency caused by excess consumption of food, drugs, alcohol or tobacco) long-term care needs will be the result of genetic predisposition or accidents – termed as “lottery of misfortune” by Hodgson (2008) – or of the natural biological process of ageing. Furthermore, this lottery of misfortune will most likely be unevenly distributed among the population or at least the need is unlikely to be correlated with the ability to secure care (more on this in the following section).

Finally, the idiosyncratic and heterogeneous nature of long-term care needs brings it full circle back to the discussion on the concept of caring. Thus, the idiosyncrasy of needs has obvious links with Baldock's (1997) notion of *user as co-producer of care* from which it results that persons with similar conditions will have specific needs, for example, as to the type of care they require or the characteristics of the carer, related to the subjective values of the person receiving care. Because needs are person-dependent, they are also heterogeneous, which stems from the nature of caring as a relationship, as each person has his/her own relationship with the carer. This has two immediate important implications: it further constrains the possibility that care can be mass-produced to benefit from economies of scale; it also raises difficulties in specifying and enforcing contracts for the delivery of care in the presence of limited information, i.e. it is a source of transaction costs (Hodgson 2008).

This section has reviewed a wide range of theoretical arguments which sustain that care has a number of characteristics that make it different from other commodities. Some of these differences, such as the fact that long-term care is based on demand derived from need, have far-reaching implications. They have, for example, potential consequences in terms of social policy and possible collective or market-based solutions for the delivery of care. As it will become apparent when debating choice in long-term care, and in particular the use of choice coupled with competition (see section 2.3 below), it is not only care that is different from conventional commodities. Markets of long-term care are themselves also different from conventional markets in several ways – which is why they are termed *quasi-markets* (Le Grand & Bartlett 1993; Le Grand 2007). These differences stem from legitimate concerns about the ability of conventional markets to deliver long-term care in the most equitable and efficient ways. As choices in long-term care nonetheless take place in a market-like context, it is important to understand not only *how* these quasi-markets are different from conventional markets, but also *why* they are different.

The next section discusses a number of arguments justifying state intervention in long-term care that are key to understanding the reasons why many argue that markets for long-term care are necessarily different from conventional markets. These arguments are also important to understand the limits or constraints on the use of competition to deliver long-term care. Finally, the next section will also assess whether the discussion about the nature of caring has been reflected on, or is indeed relevant for the arguments presented in favour of state intervention in long-term care.

2.2 CARE AS AN ATYPICAL COMMODITY – THE RATIONALE FOR STATE

INTERVENTION IN LONG-TERM CARE

The discussion about the introduction of market mechanisms and choice in long-term care has gone hand in hand with the debate about the role that the state should play in the provision of long-term care. To better understand the particular nature of long-term care as a commodity liable to be bought and sold in a 'market-type setting', it is worth examining why state intervention and regulation plays such a major role in long-term care quasi-markets. Or to put it in other words, why is long-term care not left entirely to the market or the family?

The building block of neoclassical economics is that the interplay of consumers pursuing their own interest and profit-maximizing firms operating in a competitive market would allow for the socially efficient quantity of a commodity (good or service) to be produced and allocated (Varian 2006). If left to the market, the supply of long-term care would be determined by the costs incurred in producing it, with competition giving formal providers the incentives to innovate and be responsive to the users' preferences. On the other hand, demand would reflect the satisfaction derived by individuals from the consumption of care services and their preferences. There are, however, several potential reasons why leaving the production and allocation of long-term care to the market alone may not result in an outcome that is deemed acceptable by society.

As Stiglitz (2000, p.59) correctly stresses, Pareto efficiency⁸ is an intrinsically individualistic concept as it concerns the welfare of the individual alone and not the relative welfare of others. Thus the outcome of the market may be efficient and yet be grossly inequitable and while society may be willing to accept inequities in the consumption of some commodities (e.g. luxury goods), it may not tolerate those inequities in services like long-term care that are based on need or produce caring externalities.

State intervention may also be needed in the event that markets for long-term care cannot be established at all or if there are *market failures*. The latter refer to cases where the allocation of long-term care through the market would produce an outcome that is inefficient.

⁸ Pareto efficiency refers to a situation where it is impossible to improve the situation of one individual without worsening the situation of another individual.

Still taking from Stiglitz (2000), individuals may not be able to make the best decision regarding their own well-being regarding certain commodities, because there might be externalities that they fail to take into account when deciding. The state may therefore be compelled to impose the consumption of these *merit goods*, as is the case with education or certain types of insurance. Is long-term care a commodity that entails such externalities?

The rationale for state intervention in long-term care can thus be summarised under three headings: 1) equity considerations; 2) correction of market failures⁹; and 3) merit wants. Drawing on the insights not only from mainstream economics, but also from feminist economics and social policy scholarship, each of these arguments will be debated separately in the following sections. However, it is also possible to frame state intervention in long-term care beyond economic-based arguments, for example, relying on the literature on ethics of care or on notions of care as a citizenship right. This approach will be briefly summarised under a fourth heading. It will result from this summarised account that the reasons for state intervention are interdependent. For example, equity considerations that beg for the state to assure that persons in need of care are not left wanting because of insufficient resources arise from the fact that long-term care entails caring externalities, i.e. the wellbeing of the average individual is improved by knowing that dependent people can access the care they need. Finally, this section will also attempt to analyse whether the considerations regarding the concept of caring, and particularly care as a relationship reviewed in the previous section are reflected in the arguments for state intervention.

2.2.1 STATE INTERVENTION ON THE GROUNDS OF EQUITY

Owing to Le Grand, Propper and Robinson (1992, pp.121–122), equity in long-term care can be defined in terms of: a) minimum standards, referring to a minimum level of care that everyone should be able to access, b) equal care for equal need (also referred to as horizontal equity) and c) equality of access, which means that the costs or sacrifices that people incur to access care should be similar.

As seen before, caring for dependents are relationships that can be characterised by an uneven distribution of care needs and capabilities between the carer and the person

⁹ It should be borne in mind that these market failures refer to the functioning of a market for the provision of long-term care and not to market failures that may affect quasi-markets in particular once they are established.

receiving care. However, as Knapp (1984), Bartlett and Le Grand (1993) and Himmelweit (1999) note, this uneven distribution is also present at the societal level. Those with greater care needs are also the ones with the greater incapability for self-care, but because of unequal distribution of income they are in turn also more likely to have lower resources to finance their care needs. Thus, many individuals in need would not be able to afford the care services they require, i.e. there would not be equality of access nor would the principle of equal care for equal need hold, unless the state provides care or finances it. This argument refers to the ethical value attached to the concept of need (see section 2.1.4), particularly as needs associated with long-term care can arise independently of the individual's will or actions. However, it also has certain links with the concept of care as an asymmetric relationship referred to earlier (see section 2.1.2), since individuals could find themselves dependent on the willingness of carers (e.g. family carers) to receive the care they need if they cannot afford to pay for care. Providing individuals with sufficient resources to access care could thus be seen as a way to reduce the asymmetric nature of caring relationships and to bring them closer to the disability critique's view of caring relationships as interdependent (Kröger 2009).

Le Grand, Propper and Robinson (1992, p.122) add that in long-term care equity also concerns how the costs are distributed, for "the cost or burden of social care rarely falls solely on the individuals in need of such care themselves". This is in agreement with the point made by the feminist scholarship when it highlighted the gendered dimension of caring. Inequalities are present also in the provision of care, for in the absence of collective or affordable market solutions it is women who shoulder a disproportionate share of caring tasks, with potential consequences in terms of labour market attachment or pension rights (Himmelweit 1999). Inequality is compounded by the fact that, as discussed in section 2.1.2, carers may not always have a choice when engaging in a caring relationship. This is also particularly relevant if caring entails a component of *caring about* (the relational aspect of care), as this could reinforce feelings of duty and reduce choice, particularly for family carers. While equity and efficiency are often viewed as a trade-off, Folbre and Nelson (2000, p.135) provide an argument as to why pursuing greater equity in caring could actually contribute to greater efficiency. As caring tasks have been consigned to women on the basis of status, relieving them of some of these tasks would not only distribute the costs more equitably across society, but could allow for some degree of specialisation to develop and consequently increase efficiency.

So far the discussion implies that inequalities in access to long-term care arise from the income position of individuals; state intervention could therefore operate through an income transfer. This, however, is based on the assumption that individuals have perfect command of the information and there is no unequal power (Barr 2004). The issue of information will be addressed more in-depth in section 2.2.3, but regarding the issue of holding equal power, the discussion presented in section 2.1.2 showed the limits that people receiving care may face in terms of exiting a caring relation with a carer or formal provider of care. Problems of information and unequal power may affect individuals from lower socio-economic groups in a disproportionate way, as better-off individuals may have the necessary resources to acquire information, thus making the case for state intervention beyond income transfers on the grounds of assuring horizontal equity.

2.2.2 MARKET FAILURES IN LONG-TERM CARE

The advantages of market allocation of commodities, i.e. greater efficiency, responsiveness to the consumers' preferences and expression of choice, may be severely hampered in the presence of the following *market failures*:

1. Existence of externalities: consumers or providers will not bear the full cost or accrue the full benefit of their actions.
2. Public goods: a particular case of a positive externality in which the market will undersupply or fail to supply altogether.
3. Imperfect competition: whereby either producers or consumers will have some power to determine prices through their actions, as is the case with monopolies which tend to limit supply to increase the price.
4. Imperfect information: whereby consumers and providers lack complete information about the quality and prices of what they exchange, or when one of the sides benefits from an "information imbalance" over the other (Le Grand 1991b).

Each of these market failures will be analysed next in reference to their possible application to long-term care. Before this, however, one important note on terminology. Throughout this and subsequent chapters, the term *consumer* will be used to designate individuals purchasing commodities in a market or linked to the theoretical arguments anchored around economics. The term *user* will be used to designate individuals acquiring care services (or other social services) in quasi-markets, or using those care services.

Externalities

Using the definition employed by Le Grand, Propper and Robinson (1992, p.123), externalities occur “when the activities of an individual in the market place, whether as a producer or consumer, affect third parties”. The most commonly referred externality to affect long-term care is linked with the concern that people in society may feel about the wellbeing of others (strangers) – also referred to as *caring externality* (Knapp 1984; Le Grand et al. 1992). Although individuals may not be directly linked with those in need of care, they may nevertheless be distressed if they know that the latter are not able to access the care they require or take satisfaction in knowing that the care needs of others are being satisfied. In this sense, caring externalities thus work very much like Becker-altruism discussed above, although Becker’s concept referred to specific concerns related to known loved ones. Knapp (1984, p.94) makes the case for another source of externality applicable to long-term care, whereby individuals derive satisfaction or *peace of mind* from knowing that some services not currently required by them will be available in the future if needed. He terms this “option demand externalities”, which in the case of long-term care would make this more important to individuals as they age.

Long-term care as a public good

Public goods are usually defined as possessing two specific simultaneous characteristics: they are non-excludable, i.e. it is impossible (or prohibitively expensive) to prevent anyone from consuming it once produced; and non-rivalrous, i.e. consumption by one individual does not affect the ability of others to consume it as well. Being a special case of a positive externality (Le Grand 1991b), public goods will be under-produced or not produced at all by the market, since non-excludability may allow individuals to be free-riders.

Some particular aspects or tasks of long-term care may be considered public goods. Knapp (1984, p.93) concedes that “the direct and indirect material benefits to society from the nurture, education and training of the mentally or physically handicapped are shared by all and (...) cannot really be avoided”, but he limits the public good nature of social care to just a few activities. This seems to be the case with long-term care, for in general it is possible to exclude individuals from benefiting from it and consumption by some impedes the consumption by others.

Imperfect competition and monopolies in long-term care

The existence of imperfect competition in long-term care is usually debated in relation to what extent there might be conditions for natural monopolies to occur and to the imbalance of market power between formal providers and those in need of care.

Natural monopolies may arise because the market is too small for other formal provider organisations to operate with a profit, or because of *increasing returns to scale*, i.e. once in operation average costs fall with the number of consumers. Another reason could be due to barriers to entry or exit. While some authors have debated the possibility for natural monopolies to arise in long-term care (Forder et al. 1996; Norton 2000), their conclusion seems to be that there is limited scope for natural monopolies, particularly in the home care sector.

While the scope for the emergence of natural monopolies in long-term care seems debatable, the same cannot be said about imbalances of market power between formal providers and those in need of care. In relation to this point, Norton (2000) notes that long-term care may be less technical and therefore easier for a layman to assess its quality. The previous discussion around care as a relationship and the concept of the user as a co-producer of care would seem to concur with Norton's above-mentioned argument. The same author goes on to add that it may also be less prone to require an urgent decision as with acute care and have more available substitutes¹⁰. At the same time, however, the same author recognises that in fact older people may face several constraints when deciding for long-term care: from the absence of relatives that could help with their decision, to the failure to properly consider taking-up institutional care because the thought is far from being a pleasant one. Glendinning (2008) further disputes Norton's view that decisions in long-term care may not always be urgent, as many users come into contact with long-term care in a moment of crisis (e.g. following health deterioration or the absence of any carer).

A further source of market power imbalance is the potential reliance on a third party, such as the formal provider organisation, by the person in need of care for the determination of his/her needs and preferences (see section 2.1.2) – another potential source of asymmetries

¹⁰ The degree of substitutability between formal and informal care is referred to by Anttonen, Sipilä and Baldock (2003) as the plasticity of social services and a characteristic that separates long-term care from health care, whose degree of technical sophistication is much higher and therefore allows for a much more limited substitutability.

in the caring relationship. This is a point raised by Knapp (1984), which could lead to the “upcoding of care needs”. In turn, Forder, Knapp and Wistow (1996) raise arguably a more salient issue: that the vulnerability of users could prevent them from “exiting” a relationship with the current formal provider and thus entail the latter with greater scope to reduce quality of care without fear of losing out costumers (“shirking”). Their frail condition could also limit their ability to voice their complaints. The characteristics of caring that set it apart from other commodities, namely its relational aspects, could arguably contribute to reinforcing the barriers to exit by users. To the extent that relationships entail ties that bind, this might limit competition. These imbalances would be compounded by problems of imperfect information.

Imperfect information

Problems related to imperfect information have become one of the mainstays of the critique to the neoclassical assumptions of perfectly competitive markets (see Akerlof 1970; Arrow 1963; Rothschild & Stiglitz 1976). In relation to long-term care, imperfect information may impact the process of purchasing care services.¹¹

Forder, Knapp and Wistow (1996, p.213) list some of the difficulties that prospective users may face to acquire information on quality: 1) outcomes are difficult to measure as they are multidimensional and of intangible nature; 2) the link between inputs and outputs is complex and dependent on the user’s characteristics; and 3) outcomes-measurement is complex and subject to value judgement and not liable to be easily expressed in simple indicators. The authors link these issues to the *principal-agent* problem, whereby the *agent* (the formal provider) is better informed about care than the *principal* (the user). Profit-maximizing producers may exploit this asymmetry of information in their favour by selecting users not based on need but on profit-maximisation (*cream-skimming*), or by *upcoding* the users’ care needs or *shirking*. However, the potential for imperfect information also arises from the nature of caring as a relationship, such as the link to the experience good nature of care in general and to caring relationships in particular; and the link to Baldock’s (1997) concept of *user as co-producer* discussed earlier. In addition, the extent to which long-term care may be considered an example of an experience good means that quality may only be satisfactorily

¹¹ Imperfect information may also impact the viability of the insurance market for long-term care as it may create problems of moral hazard and adverse selection (see Barr 2010 for a comprehensive discussion on this). As insurance for long-term care is not directly linked with the core subject of this thesis, issues pertaining to imperfect information in insurance are not discussed here.

measured after consumption takes place. As needs may evolve with time, users may only have imperfect information regarding the cost of long-term care as well.

These difficulties may not be insurmountable if consumers can gain experience with several carers, or if it is possible, to access the necessary information in advance. However, as Knapp (1984) and Le Grand, Propper and Robinson (1992) recognise, users of long-term care are usually not able to shop around or gain experience and knowledge from previous contacts with different formal provider organisations as they would do with other commodities. The state may step in and regulate the disclosure of information on quality indicators in care homes, as has happened in countries such as The Netherlands or Sweden (Rodrigues et al. 2014). However more fundamental problems of information processing ability may exist. Glendinning (2008), for example, further argues that the health and social condition of those in need of care is highly changeable and in many cases uncertain, which means that acquired information may rapidly become obsolete. The nature of care as a relationship compounds on these limitations, for not only does it require information on something that is by nature intangible (i.e. relationships), but it is also highly dependent on the user itself. Indeed the user is also a co-producer of the relationship, to use Baldock's (1997) concept. The salience of care as a relationship thus seems to carry very clear implications for imperfect information in long-term care.

2.2.3 LONG-TERM CARE AS A MERIT WANT

As discussed above, the state may intervene in the production of public goods because of the consequences of the *rational behaviour* of individuals (i.e. behaviour that is in conformity with neoclassical economic assumptions). Regarding merit wants, one way to frame state intervention is to consider it as an overruling of the individuals' preferences because individuals may not always be the best judges when it comes to their own welfare (Stiglitz 2000).

In terms of social policy, it is easy to see how merit wants may be a less than consensual argument for state intervention. Some would argue that this reflects a *state knows best* view that is in a sense paternalistic, while the notion that the state *actually* knows better than individuals may be questioned on several grounds (see New 1999; Cullis & Jones 2009 for an exposition of these arguments). Furthermore, in terms of long-term care, this paternalistic intervention may be at odds with the call for greater empowerment for users and the individualisation agenda that calls for personalised care.

However, a more recent strand of literature has framed state intervention based on merit wants around the recognition that individual behaviour may not always be motivated by self-interest and may thus systematically deviate from the assumptions of the *homo economicus* (Parker & Clarke 1997; Bowles 1998; Jones & Cullis 2000; Jones & Cullis 2002; Cullis & Jones 2009). This interpretation of merit wants may be pertinent for long-term care, given the discussion on motivations presented in section 2.1.3. Drawing from the typology of human behaviour that could potentially call for state intervention on the grounds of merit wants set forth by Head (1988; cited by Jones & Cullis 2002, p.84) and Jones and Cullis (2000) what are the characteristics of long-term care that could make it a merit want?

Firstly, unlike the *homo economicus*, real individuals may have difficulties in making decisions over their life-cycle, particularly if these decisions imply having to think about potentially unpleasant outcomes, such as needing care (Jones & Cullis 2000). Individuals may exhibit myopic behaviour and thus fail to gather adequate and sufficient information about available care options for when in need of care and later regret this decision when in old-age (Parker & Clarke 1997).

The second feature of long-term care as a merit want is linked with how human beings are able to make choices in the presence of (almost) complete but yet complex information. This is a different issue from lack of perfect information discussed in the previous section as it involves what New (1999) called an “information processing problem”. The nature of decisions involved in some cases when long-term care is needed may be such that individuals are unable to correctly judge the suitability of care required (rehabilitation being probably one such example). This is akin to Simon’s (1957; cited by Williamson 1975) concept of “bounded rationality” that refers to the cognitive limits to acquire, accumulate, process and transmit information even if it is available.

Glendinning (2008) offers a discussion of some of the features of long-term care that may limit the ability of those in need of care to process the necessary information needed for informed choice. Besides the possibility that information may rapidly become redundant as a result of changing needs, some of those in need of care are individuals whose ability to grasp the full range of consequences from their decisions or to understand their own circumstances may be hampered – for example, people with dementia or older adults with learning difficulties. Choice may entail substantial implications for the future, raising the issue of “cost of regret” (Thaler 1980). In circumstances where the anticipated regret is high, individuals may prefer to delay or avoid making decisions (Lerner & Keltner 2000) or trust others to make decisions for them, as Thaler (1980) noted for medical care.

The final argument in favour of long-term care as a merit want goes back to the above discussion on intrinsic and extrinsic motivations and endogenous preferences. The argument, as presented in different ways by Le Grand (1997; 2003), Bowles (1998) and Jones and Cullis (2000; 2002), among others, is that individuals' preferences are shaped by institutional settings. Without needing to repeat what was discussed in section 2.1.3, if intrinsic motivations are important to the provision of long-term care, market values could induce knights into displaying knavish behaviour¹², or erode the trust necessary to conduct transactions where quality is difficult to assess and barriers to exit high. In the presence of such circumstances, it could prove more adequate to rely on collective solutions for the provision of care.

The arguments that justify state intervention modelled around care as a merit want seem to further question the notion of the user of care as a rational consumer. In this sense, there are some links with the previous discussion on how caring behaviour may not conform with the pursuit of individual self-interest (see section 2.1.3). However, the deviations from the assumptions of the *homo economicus*' behaviour presented here stem not from different motivations, but from limits to the use or ability to process information. Both are relevant in the context of user choice (see section 2.3).

2.2.4 CARE AS A CITIZENSHIP RIGHT

The rationale for state intervention on long-term care has thus far been built around arguments that are anchored on economic theory or that at least can be framed by it. However, it is possible to broaden the scope of arguments for state intervention by building on the contributions from the ethics of care and the disability critique.

In her analysis of caring, Kittay (1999; as cited by Fine 2007, p.74) refers to care as a "necessary labour". State intervention can be viewed as necessary to even the playing field for carers, thus providing them with the same opportunities and rights as those that do not have this responsibility. This argument is close to the discussion on equity presented above, which is still very much grounded on the notion of citizenship as attached to labour market participation.

¹² Bowles (1998) provides an extensive survey of literature on endogenous preferences, while Jones and Cullis (2000) explore the impact of endogenous preferences on the economic theory of altruism and private donations to charities in the UK.

However, if dependency is recognised as a natural part of the lifecycle (Knijn & Kremer 1997; cited by Fine 2007; and Sevenhuijsen 1998), state intervention in the long-term care sector can be framed around the concept of care as a citizenship right. This reasoning is best summarised in the following words:

[care for others] can nowadays only be fulfilled at the cost of what is perceived as the most vital aspect of social citizenship: labour participation. Hence, caregiving leads to a reduction in citizenship status. Rather than focusing on labour-participation alone, we argue for the reconceptualization of citizenship which acknowledges that every citizen will be a care-giver sometime in their life: all human beings were dependent on care when they were young, and will need care when they are ill, handicapped, or frail and old. Care is thus not a women's issue but a citizenship issue. (Knijn & Kremer 1997, p.332; cited by Fine 2007, pp.95–96).

In this line of thought, Sevenhuijsen (1998, p.110) argues that “the potential to maintain intimate relations and care for others is an important formative value”. The relationship nature of caring debated in section 2.1.1 has an intrinsic value in itself and not only as a response to care needs (Fine 2007). Therefore, the state should play an enabling role for individuals to be able to develop those intimate relations. Her reasoning is built around child custody rights and how both parents should be provided authority rights not based on a sense of duty or protection against abuse by the other part, but rather to allow both parents the development of intimate caring relationships. Conversely, this could easily be transposed to care for older people: state intervention would aim to provide the means for all – men and women, carers and those in need of care – to fulfil their caring relationships.

The case made by the disability critique on the other hand is built around the notion of state intervention as an empowering tool that offers agency to those in need of care. The disability critique has emphasised that caring is an exchange between the carer and the person in need of care (Fine 2007). Providing the latter with enough resources is not just an issue of equity in the terms discussed above – for example, ensuring that care needs are matched with the means to access it – but a matter of providing those in need of care with agency to be in command of their own care. This equates to the call made by the disability critique for the exchanges involved in caring to be approached from the perspective of those receiving care. Indeed some of the state interventions built around cash benefits provided directly to those in need of care can be framed within this rationale. As it will become apparent when discussing quasi-markets and the use of cash benefits in latter sections, this will not

necessarily mean the dismissal of the market but rather its use as also an empowerment tool namely through choice.

The arguments for state intervention in long-term care presented throughout this section provide an important background to understanding some of the constraints in the use of conventional markets to deliver long-term care. Some of these constraints pertain to issues of equity, as markets cannot always ensure that those most in need of care will be able to afford it. Other constraints include the possibility for market failures to arise, which can result in inefficient outcomes (e.g. as a result of imperfect information). Given the nature of long-term care, these may have particularly serious consequences for those most in need of care by driving up prices or lowering the quality of care. Finally, some arguments in favour of state intervention are related to the need to correct the outcomes of choices made by users who may not act as rational consumers (in the sense of neoclassical economics), or may not be able to make the decisions that best serve their interests. Together with arguments about motivations reviewed before (see section 2.1.3), these provide further credence to the notion that users of long-term care may act differently from conventional consumers.

The seemingly valid justifications for state intervention in long-term care presented here are important to frame the discussion about the use of choice, coupled with competition, to deliver long-term care. As it will become apparent in the following section, many of the arguments in defence of limiting user choice rely on concepts used in this section, such as equity or information asymmetries. Yet, other justifications for state intervention presented here come closer to some of the arguments employed by those favouring user choice. For example, state intervention modelled around the provision of sufficient resources to those in need of care bears resemblance with discourses built around the notion of user choice as an empowering tool.

A salient feature of the literature surveyed in this section is the absence of any reference to the specific nature of caring in the discussion around state intervention. The argument of care as a citizenship right comes closest to incorporating the notion of care as a relationship to justify state intervention, but even this falls short of fully considering the issues raised by the special characteristics of care as a commodity. This gap is all the more significant as there are several aspects of care as a (special) commodity that bear direct relevance for equity and market failures, as this section demonstrated. For example, state intervention may be fundamental to allow users the necessary means to address asymmetries in caring relationships (e.g. by providing them with financial resources to pay carers). More importantly, the greatest scope for market failure in long-term care arguably seems to be

imperfect information. This is of direct relevance to the concept of care as a relationship. On the one hand, problems of imperfect information could be enhanced by the relational aspects of care. On the other hand, imperfect information concerning relationships could have direct implications for the choice users have in the context of quasi-markets of care.

2.3 CHOICE IN LONG-TERM CARE

A number of reforms undertaken in welfare policy in the past decades have sought to increase the reliance on market mechanisms by welfare states, including long-term care (Taylor-Gooby & Lawson 1993; Pavolini & Ranci 2008). The justifications for this movement towards markets in welfare policy have been strongly debated and the several reasons put forward by social policy scholars should probably be read more as supplementary rather than in opposing terms. The arguments nevertheless relate to the issues of efficiency, autonomy and care as a citizenship right referred to in the previous section.

From a more theoretical standpoint, the collectivist nature of social services came under the criticism of a series of developments in economic theory, that both questioned the underlying behavioural assumptions on which traditional social services were based and their ability to deliver outcomes in an efficient manner (Jordan 2005; Le Grand 1991b). Thus, the newfound reliance on market mechanisms can be seen as being rooted in a shift from the idea that the behaviour of formal providers and users is driven by altruism and compliance, to one that sees their behaviour as being best characterized by the pursuit of self-interest (Taylor-Gooby 1999), in line with public choice and New Public Management (NPM) theories (see Mueller 2003 for a review of public choice theories; and Hood 1991 on New Public Management).

Another stream of thought places these transformations in the context of wider socio-economic changes. *Traditional industrial* societies gave way to a *post-industrial* world characterised by an ageing population, as well as cleavages defined more by age and gender than class; while globalisation of markets and more demanding citizens have also put increased pressure on traditional social services (Taylor-Gooby 2008, p.168). As even those defending the role of collective social services recognise, users or citizens had only limited weight in the planning and delivery process of public services (Jordan 2005, p.149). This has clashed with the demands for greater influence and responsiveness made by better articulated citizens that had lived their adult lives in a consumerist society (Giddens 1994; as cited by Taylor-Gooby 2008; Higgs et al. 2003). Under this latter reasoning, introducing market mechanisms in public social services can be seen as a way to secure support and legitimacy from voting citizens by aligning these services with their private counterparts with

whom citizens interact (Glendinning 2008). These fundamental changes in the way social services are conceptualised and delivered have thus placed a greater focus on how individuals are able to “design their own social policies”, as Klein and Millar (1995) have so aptly framed it, or to put it in other words, on the role played by choice.

In discussing choice within the context of long-term care, it is possible to distinguish between its *instrumental value*, i.e. choice as a means to achieve other ends, and its *intrinsic value*, i.e. choice as desirable end in itself (Bartlett & Le Grand 1993; Dowding & John 2009). Taking the former approach, choice is viewed as a fundamental tool to achieve better efficiency and service responsiveness by increasing competition in the context of quasi-markets, while the latter is linked to the consumerism discourse (Glendinning 2008). This distinction serves as the framework for discussing choice in long-term care in this section. However, trivial as the term choice is in everyday use and recent policy discourse, it remains nevertheless a concept that is far from having a precise and clear meaning when it comes to long-term care. As Fotaki et al. (2005, p.26) argue “choice is a many-sided, diffuse and value-laden concept”. Therefore, a precondition to discuss it along the lines mentioned above is to firstly define what is meant by choice.

2.3.1 DEFINING THE DIMENSIONS OF CHOICE: WHO CHOOSES WHAT

While acknowledging that users can in theory choose over a wide range of dimensions in public services, Le Grand (2007) defines choice around five questions: where, from whom, what, when and how. The first refers to the choice of care setting where care is to be provided (e.g. residential care or care in the community). In the strict sense, *from whom* relates specifically to the person providing care, i.e. the carer that interacts with the person in need of care (e.g. the agency carer or another paid carer). In a broader sense it refers to formal providers of care, whether formal organisations such as home care agencies or personal assistants. Choice over *what* relates to the choice of service, treatment or care package (e.g. tasks to be performed by the carer); while choice over the timetable of service delivery (e.g. when meals are to be served or when does the carer come by his/her house) is linked to the question of *when*. Finally, *how* refers to the mode of access of services or to the way that services are provided (e.g. the way personal care is delivered).

Given the characteristics attached to care, these five questions would in theory capture most of the important dimensions of choice for users. As part of the creation of quasi-markets in long-term care, the ability to choose among different types of providers in a mixed economy of care is regarded as particularly important in enabling competition (Forder et al. 1996).

However, users themselves may attach a greater importance to the choice of whom is providing care and when. These issues will surface again when discussing the instrumental and intrinsic value of choice, as well as the concrete case of the development of choice in England.

Le Grand (2007) also recognises that another important dimension in defining choice is about who has the power to make the decisions. This can be users themselves or agents acting on behalf of them such as GPs or case managers¹³. While applying their analysis on health services, Fotaki et al. (2005) stress that users may not always have the power to choose, either because they lack cognitive skills (e.g. patients whose health condition limits their ability to signal their preferences), due to ethical considerations (e.g. self-harm and the possibility to choose for others) or because they delegate their decision powers to an outside expert (e.g. the GP or case manager). In the context of choice in long-term care, the issue of who is empowered to choose is of particular importance. Indeed it links to the above discussion regarding the mutual asymmetries and dependencies established in a caring relationship and to issues of agency.

In the present research, choice is hereafter defined along the dimensions and terminology depicted in Table 2.1. Stemming from *agency* – who is entitled to or has the power to choose – the following dimensions refer to the realm of possibilities of choice, i.e. to the dimensions of care over which those empowered with agency may exert choice as defined by regulations or institutional design of care benefits. These dimensions refer to the *choice that is allowed*.

¹³ Regarding to whom the possibility of choice might also apply – this may be labelled as choice over the “identity of the gatekeeper” (6 2003).

Table 2.1 – Delimiting choice

Dimension	Agency	Where	From whom	What	When	How
Concept and example	Who is empowered to choose. Example: users, individual agencies (GP) or collective agencies (local authorities).	Choice over the care setting: at home, in the community, or in an institution.	Choice over the identity of the person providing care or at least the formal provider organisation. Example: private companies, non-profit organisations, public providers or personal assistants.	Choice over the typology or content of services provided by the carer/formal provider organisation. Example: house cleaning, personal hygiene, nursing care, meals (including their composition).	Choice over the timetable of care provided. Example: choice over the time when meals are served or for how long the carer provides care.	Choice over the manner services are delivered. Example: choice over the way baths are given or how meals are served.

Source: Adapted from Le Grand (2007)

The dimensions where, from whom (both in the strict and broad sense), what, when and how may serve as a framework for analysis of choice in relation not only to what is allowed but also to two related but yet different concepts referred by Klein and Millar (1995, p.308): *capacities for choice* and *choice set*. The former of these concepts refers more closely to the ability to choose or to make choices come true, which includes not only the choices that are allowed, but also the choices that people are able to make because they possess the necessary resources, namely information and financial resources. The latter of Klein and Millar’s concepts refers to the possibilities available from where to choose from, for example, the number of different providers or care services available. It is thus important to distinguish between the related concepts of *choice that is allowed*, the *capacities for choice* and the *choice set*. For example, users may be entitled to choose between providers (choice allowed), but they may lack the necessary information about the available providers (capacity for choice) or the reality of the care market may be such that there are only a limited number of providers to choose from (choice set).

Although the dimensions presented in Table 2.1 provide a delimitation of choice, they still leave out the question of how to measure it. Dowding and John (2009) provide a synthesis of the difficulties involved in measuring choice in absolute terms, i.e. using a “cardinal perspective” equivalent to counting the number of choice options. Adapting their example, it is not clear that more formal care provider organisations offering relatively homogeneous

care services entail more choice than fewer formal care providers with more differentiated care services. Furthermore, increasing the number of providers or giving choice over a wider range of dimensions may entail costs, for example driving preferred providers out of the market or increasing transaction costs that result in a reduction of overall welfare. Dowding and John (2009, p.231) thus make the claim that choice should be measured not against a *hard definition* – associated with a simple head count of number of providers or dimensions of choice – but rather through the lens of the net welfare gains it could entail, both in terms of its instrumental and intrinsic value. This is the view followed in analysing choice within the present research as well.

2.3.2 CHOICE AS AN INSTRUMENT IN QUASI-MARKETS

The discussion over the merits of choice as an instrument to achieve other ends is associated with its use together with competition in the context of quasi-markets (Bartlett & Le Grand 1993; Le Grand 2007). In a competitive market, choice is the driver of both allocative and production efficiency (Dowding & John 2009). Consumers are able to choose from different suppliers and thus signal their preferences in terms of the commodities they wish to buy. Suppliers faced with competition have the incentive to produce not only what the consumers want (allocative efficiency or responsiveness), but to do so at the lowest possible cost (production efficiency), for otherwise consumers will vote with their feet and choose a different supplier. When choice is curbed by whatever reason, such as when there are monopolies, suppliers are able to increase their profits at the expense of the consumers.

Quasi-markets implemented in long-term care are intended to mimic this process by replacing public monopolies in the delivery of care by multiple providers competing for funding (Le Grand & Bartlett 1993). However, quasi-markets deviate from standard markets in important dimensions (Le Grand & Bartlett 1993; Le Grand 2007). Thus, not all formal providers operating in quasi-markets will be driven by profit-maximization, given that many will be non-profit organisations, which may cast some doubts on their ability to fully respond to market incentives. On the demand side, depending on how the choice is formulated, users' demand may not be expressed in terms of money but through a voucher or a third party purchaser that makes the decisions on their behalf. Furthermore, price in quasi-markets does not result from the interaction of supply and demand, for the budget of purchasing agencies will be administratively set and prices are most likely strictly regulated. Therefore, prices in quasi-markets do not transmit accurate information about the demand of users and the production conditions of formal providers, and some might not face *hard budget* constraints (Le Grand & Bartlett 1993).

The main arguments for choice within quasi-market settings are that it would bring efficiency gains, improve the responsiveness of formal providers to users' needs and preferences and improve equity (Le Grand 2007). This was contrasted to the previous monopolistic public provision that was deemed to be inefficient in the delivery of care and more worried about satisfying welfare bureaucracies than the users they were supposed to be caring for (Le Grand 1991b). Choice coupled with competition would enhance efficiency, i.e. would produce the highest level of quality at a given cost, and responsiveness through the workings of the market forces as described above. However, unlike standard markets, Le Grand (2007) among others also argues that quasi-markets could potentially deliver a more equitable outcome. Choice would provide less well-off individuals with what Le Grand (2006, p.704) refers to as "sharper elbows" with which to make their claims heard by formal providers. It would also allow for the ability to purchase care to more closely relate to the care needs, since the purchasing power is defined by the voucher or cash benefit and not entirely by the individual's income.

Thus, in the context of quasi-markets, the instrumental value of choice is only as good as its contribution to increase efficiency, responsiveness of formal providers and equity. It is worth reviewing some of the theoretical considerations regarding choice and each of these aims.

Efficiency

The main mechanism by which choice impacts efficiency is through the possibility that those purchasing care (users or public purchasers acting on their behalf) may exit the relationship with the formal care provider organisation and choose a different one. That is, whoever has agency to choose is allowed and able to decide on the *from whom* dimension of Table 2.1. This rests on two critical assumptions, however: that there are enough providers to choose from, i.e. enough competition, and that individuals are willing and able to *exit*, or that at least the threat of doing so is credible enough to induce behavioural changes in providers – i.e. that the market for long-term care is contestable.

The first of these assumptions links the issue of choice with competition and in fact part of the debate around the instrumental value of choice seems difficult to disentangle from the issue of how best to approximate quasi-markets to a competitive market. Following this line of thought, users' choice is enabled by competition and for this a number of institutional conditions must be in place (Fotaki et al. 2005). There should be: a sufficient number of buyers and sellers so that no one profits from excessive market power; no barriers to entry or exit the market by providers; precise information about the price and quality of care; low

transaction costs and the participants' behaviour must be driven by market incentives (Bartlett & Le Grand 1993; Fotaki et al. 2005; Greve 2009). These conditions denote a clear influence from neoclassical and institutional economics and their view of markets as the best mechanisms to produce optimal, i.e. Pareto efficient, outcomes.

The potential sources of market failures in long-term care have already been discussed in the previous section and will not be repeated here. Instead, the focus is on the arguments as to how increasing choice may impact the above conditions for competition and in turn efficiency.

In his 1991 article on quasi-markets, a more sceptical Le Grand (1991a) worried about the added production costs that allowing for greater choice might induce in comparison with monopolistic public provision. His concern was linked with possible rising labour costs, as a previously monopsonic employer is replaced by several formal provider organisations competing to attract workers. Furthermore, quasi-markets demanded the setting up of an infrastructure which allowed for transactions between purchasers and providers to take place and be enforced, most notably for information on quality to be defined and collected or else risk *provider capture*, which could mean added costs. According to transaction costs economics, efficiency gains are more likely to arise through the use of market mechanisms when contracts are easy to specify and enforce and outcomes easily quantified and observed (Williamson 1975; Williamson 1985) – hardly the case with long-term care. In fact, Le Grand (1991a) also expressed concerns that if assessing quality of outcomes proved complex, then inputs could become the yardstick with which to measure quality and this could put an upward pressure on production costs – causing (inefficient) over-investment to signal quality, akin to an “arms race” (Le Grand & Bartlett 1993).

Le Grand's concerns were voiced in a context where the purchasing of care services was not to be made by users themselves but through a monopsonic purchaser. Glendinning (2008) and Baxter, Glendinning and Greener (2011) discuss how changing the agency (i.e. who has the power to choose) could impact the instrumental value of choice, namely on efficiency, in the context of reforms introduced in England. Providing users with the power and means to choose would mean replacing the monopsonic buyer with multiple buyers, thus coming closer to the workings of a standard market. Analysing the potential effects on efficiency from an ex-ante position reveals somewhat contradictory insights.

On the one hand, there could be efficiency losses since individual users may lack the bargaining power of single large purchasers. Economies of scale derived from block contracts

would also probably be lost, as formal providers would now compete to attract individual users (Glendinning 2008). This would also mean a more fluid and unstable environment for formal providers that could hamper their ability to plan and create greater instability for the working force, while also increasing transaction costs associated with gathering information on users' needs and characteristics and providing them with accessible information to enable choice (Baxter et al. 2011). Finally, taking the cue from research on user behaviour in health care, it is not a foregone conclusion that users of long-term care will act as consumers in a standard market (Greener & Mannion 2009).

On the other hand however, personalised funding and choice by users could increase competition. It could allow for local monopolistic formal providers to be contested by new entrants that would no longer face entry costs associated with negotiating or creating capacity to apply for large block contracts (Baxter et al. 2011). Small formal provider organisations could expand to cover niches and slowly build capacity as they gather users. Allowing users to pay for informal carers or hire personal assistants could also be seen as further expanding the available pool of possibilities of care provision.

The instrumental value of choice to bring about improvements in efficiency could also come into question if users are not able to exert their power to exit and this could happen for a number of reasons: because of need (Needham 2006), endogenous preferences (Taylor-Gooby 1998; England & Folbre 2003; England 2005) and lack of consumer sovereignty (Eika 2009).

As stated in section 2.1.4, demand for long-term care is a derived demand that arises because of need rather than want. As the need will most likely be permanent, users may have limited possibilities to exit the market of care, unless they opt for informal care – which may not always be available or sufficient to satisfy care needs. These barriers to exit may be even greater in the case of people with specialised care needs (Glendinning 2008).

The feminist scholarship reviewed above has highlighted how carers may develop a bond or sense of attachment with the person they care for, which could preclude them from exiting that relationship (England & Folbre 2003; England 2005) – termed *endogenous preferences* (Bowles 1998). This could also apply to the person cared for. Consumer choice theory is built on the assumption that consumers decide after weighing all available options without being influenced by the environment or context in which choice takes place (Taylor-Gooby 1998, p.14) – a detached consumer. However, the relational dimension of care may lend itself to the

establishment of attachments and ties that bind between the carer and the person cared for, thus limiting exit.

There is also the question of potential lack of, or limited consumer sovereignty, as alluded to in section 2.2.3 and exposed by Eika (2009, p.133), i.e. users of long-term care might “have insufficient physical, mental, or social capacities to safeguard their personal interests”. It is worth noting that this does not arise due to asymmetric information as is the case in health care. In the latter case the GP has specialised knowledge about the diagnosis, available medical treatments and their quality and thus has an information edge over the patient. Instead, for Eika, limited sovereignty suggests being unable to decide the best option even if enough information is available (e.g. due to diminishing cognitive ability) or to monitor or enforce decisions. The example presented is that of users with dementia, which may have their decision-making skills hampered by their condition and lack the credibility to enforce their complaints (Eika 2009; Glendinning 2008). The author recognises that the issue could be partially addressed through representatives (e.g. relatives), but besides the obvious *principal-agent* issue, this solution could also have implications for the possibility of exit as users may wish to remain geographically close to their representatives.

Finally, the instrumental value of choice to raise efficiency may come under question if the assumptions on which consumer choice is built on do not fit the actual decision-making process of individuals, particularly in long-term care. Quite a wide body of literature has addressed the actual process by which humans make decisions (see for example Fotaki et al. 2005 for a survey of the several theories applied to health care; or Beresford & Sloper 2008 for a survey of psychological theories regarding choice) and authors such as Schwartz (2004) presents several examples of how consumption decisions may depart from what neoclassical economic theory would dub as rational.

Thus, individuals may be much more frugal in the use of available information and resort to mental simplifications or heuristics that speed up the decision-making process and are used as a strategy to deal with Simon’s concept of “bounded rationality” (Kahneman & Tversky 1979). Furthermore, heuristics can be affected by framing – literally how information is presented, or phrased – or by the availability and salience of information (Schwartz 2004, p.56ff). For example, people’s choice of long-term care provider may be more influenced by a single vivid testimony of one user with which they come into contact, than by the information displayed by several quality indicators. In their seminal paper in which they expose their *prospect theory* under conditions of uncertainty, Kahneman and Tversky (1979) convincingly argue that when making their decisions people weigh the gains and losses in comparison to a

reference point and not in absolute terms. They believe people are risk averse when deciding upon potential gains and more prone to take on risks when it comes to losses.

As Schwartz (2004, p.70) puts it, however, “The fact is, we all hate to lose”. If people experience a greater dissatisfaction from losing what they have than from potential gains, this coupled with their loyalty towards a known carer could form a powerful barrier to exit in long-term care. Similarly, several examples anchored in psychological research point towards the impact that emotions can have in decision-making. It is not only regret from decisions that can influence choices (see section 2.2.3 above), but also the individual’s emotional state at the time when decisions are made. In this respect, Lerner and Keltner (2000) found that fear can lead people to make over-conservative decisions – a finding that could apply to long-term care where decisions are often made under stress (Baxter & Glendinning 2013)¹⁴.

The previous sections have provided reasonable arguments as to how long-term care may be different from other commodities traded in markets (see section 2.1) and why conventional markets may not be able to deliver long-term care in the most equitable or even efficient manner (see in particular sections 2.2.1 and 2.2.2). The literature discussed above further questions the view of users as consumers of care that is central to the functioning of markets.

Responsiveness

While choice and competition may increase production efficiency under specific conditions, it could also improve allocative efficiency, i.e. render formal providers more responsive to the users’ needs and preferences. Again, the mechanism by which responsiveness is enforced is through users exiting their relationship with a provider if unsatisfied about the quality or characteristics of services delivered.

Prices usually provide market signals about the preferences of consumers and thus guide suppliers in providing the variety of commodities that consumers are willing to purchase. As discussed before, prices in quasi-markets may lose some or most of their value as market signals because they may not reflect demand and supply. This is one of the key differences between quasi-markets and standard markets and one that is likely to impact the responsiveness of providers. Prices, but also public budgets (even if provided to users in the

¹⁴ This may have implications for the instrumental value of choice as well, since negative emotions in the process of making decisions (e.g. fear) may lead to more conservative choices as discussed in section 2.3.2 above.

form of cash or vouchers), are likely to be administratively set by public authorities and there might be a gap arising between the market signs thus provided and users' preferences. An example of this is provided with the German long-term care insurance that provided higher benefits for institutional care use for those with lower care needs, thus signalling and incentivising the take-up of institutional care (Rothgang & Igl 2007).

A key issue in improving responsiveness through choice relates to who is empowered to choose, i.e. who has agency to choose. If purchasers are not the users themselves, then one might question to what extent their choices are aligned with those of users. Similarly, if purchasers act as *knaves* rather than *knights* (Le Grand 1997), what incentive should they adopt to defend the users' interests. Similar doubts over the responsiveness may arise if users are constrained in their choice over the above *where, what, when, how* and *from whom* dimensions of care. Baxter, Glendinning and Greener (2011) have argued that personalisation of funding may reduce barriers to entry and thus improve the responsiveness of providers. Nonetheless, the flipside of choice is that by using their exit option, users may push some providers out of the market which means that the choice of some users could limit the choice of others (e.g. limit the choices of those who had chosen one provider that is forced to leave the market) (Greve 2009).

This leads to the discussion of whether responsiveness may only or best be achieved through choice and exit, or rather through other mechanisms such as Hirschman's (1970) concepts of "voice and loyalty". In the latter case, users express their opinions not by exiting but by voicing their opinions to managers or authorities. Le Grand (2007) concedes that voice has its advantages since it emanates from the users' needs and wants, providing much richer information than exit - it can also probably better accommodate for the collective nature of public services. In the end, however, Le Grand still opts for choice because he sees voice as not carrying a sufficiently strong incentive to improve efficiency and because those whose voices are heard are probably the most affluent and educated (equity issues).

The matter however is probably best approached by considering the conditions under which choice or voice may be more suitable. Based on the analysis of choice and voice mechanisms in long-term care in four European countries, Egger de Campo (2007) discusses conditions which may hinder the effectiveness of choice or voice. Thus, the power of exit may be limited if simply there are no or limited alternatives to shift to. For instance, this can be caused by regulations that harmonise services, quality standards and prices; or if users attach a greater value to loyalty, for example, maintaining the relationship with the carer; or if barriers to entry are high, as it is the case when there are waiting lists and older people may fear losing

the little care they receive and get back to the end of the queue. On the other hand, voice may be left unheard in any of the following cases: if users must compete for scarce services (demand exceeds supply) or face monopolies, in which case providers may simply be willing to drop the more *vocal* users; if users act isolated and thus their complaints are uncoordinated and unknown to other users; and finally, if the costs associated with voice are high, thus rendering this mechanism a privilege of those who can afford the costs – the latter is an argument in line with Le Grand’s reservations on how equitable voice can be.

Equity

Standard markets driven by the *cash nexus* are often thought of as replicating or magnifying social and economic inequalities and indeed public provision of social services has often been justified on the basis of its ability to “break or even redress the relationship between individual (or household) income and levels of welfare/well-being” (Clarke et al. 2005, p.168). Re-introducing market incentives in the provision of care could thus run the risk of increasing inequalities. Although quasi-markets mimic the functioning of a conventional market, Bartlett and Le Grand (1993) nonetheless claim that unlike the latter, the outcomes of the former are likely to be much more equitable as benefits (in kind or cash) are allocated on the basis of need.

The question of whether increased choice is compatible with equity is, however, more complex and it hinges on the accessibility of information (see Baxter et al. 2008 for a review on the subject), as well as on the inability of providers to cream-skin the market, i.e. to discriminate against some users.

The exercise of choice implies access and use of information about care providers and this can not only impact the uptake of care services, but also determine the outcome of care (Baxter et al. 2008). As Appleby, Harrison and Devlin (2003, p.35) point out “Choice is not a free good” and it may involve costs, such as gathering information. If these costs are significant, only those with sufficient resources will be able to afford searching for information. Similarly only those with better cognitive skills or access to social capital will then be able to extract the most out of it to their advantage. Access to social capital in particular may be an important enabler of choice when decisions are made under conditions of particular duress. Thus, “Asymmetric information can further increase the risk that those less informed will lose out” (Greve 2009, p.549).

In a context of demand for care outstripping supply, choice could mean not only that providers compete for users, but users may find themselves competing for care as a scarce resource (Scourfield 2007). Providers may thus be presented with an opportunity to cream-skim, i.e. to select from the pool of users the ones that present better opportunities for profit or that are easier to handle or cause less disturbances to the functioning of the organisation (Glendinning 2008). In fact, in the early stages of implementing quasi-markets in long-term care in England, Knapp et al. (1994, p.147) warned that “residualisation of the poor may be the price to pay for freedom of choice for the rich”. Cream-skimming may also arise because of the incentive structure imbedded in the payments that providers receive or in the contracts established with purchasers (Bartlett & Le Grand 1993), for example, if the payment received by the provider is not linked to the care needs and costs incurred with the user.

When arguing that choice may be preferred to voice on the grounds that the latter favours the more affluent individuals, Le Grand (2007) seems to echo Hirschman’s (1970, p.15) view of choice as “neat” and “impersonal”. However, exercising choice over care may not be such an impersonal and neutral affair as the theorisation of choice would lead us to believe. Clarke, Smith and Vidler (2005, p.172) argue that the exercise of choice calls for the use of “symbolic capital’ (e.g. manner, style and mode of speech) that would give some users an edge and make them seen as more adequate in the eyes of providers.

2.3.3 CONSUMERISM AND CHOICE AS AN INTRINSIC GOOD

Choice could also be seen as having a value in itself, as possessing an intrinsic value independent of its instrumental use to achieve other ends. In trying to answer why choice in social services could be valuable in itself, Dowding and John (2009) advance several arguments. Firstly, that people enjoy the process of choosing, or at least derive a sense of security and control from it, since choice is what people came to expect from living in a consumerist society. Furthermore, people care not only about the outcomes, but about the process itself (e.g. while nursing care received may be similar, the way in which it is provided may entail quite different levels of satisfaction for the user). Exerting choice helps people discover their own preferences and choice enables people to feel in control (at least to some extent) of the services they consume. More generally choice can be seen as the embodiment of consumerism underpinned by:

the belief that individual choice is an intrinsic good in itself and should therefore be the dominant factor shaping the activities of publicly funded welfare services so that

these can be more closely attuned to individual circumstances and to satisfying individual preferences and priorities. (Glendinning 2008, p.458)

There are evident links with the goal of achieving better responsiveness of public services, but the consumerist rhetoric goes well beyond this. In her critical synthesis of the developments of choice for disabled and older people in England, Glendinning (2008) links the arguments that support choice as having an intrinsic value with the notions of: i) autonomy, self-determination and citizenship, ii) independence, iii) power and iv) choice as an outcome of care. As it will become apparent there are obvious contact points between the first three of these notions and the disability and feminist scholarship surveyed in sections 2.1 and 2.2.4.

The quest for autonomy has been central to the disability scholarship and rights movement, which has questioned the extent to which care should be defined around the absence of autonomy (Fine & Glendinning 2005). Without repeating the arguments presented in the sections aforementioned, choice can therefore be viewed as both a pre-condition and recognition of full citizenship status for those in need of care. For Clarke, Smith and Vidler (2005, pp.179–180) choice as an embodiment of autonomy also results from the process of fighting against the subordinations and limitations inherent to the traditional public welfare services. These were often built around forms of knowledge that derived from the professional or state power or expertise and that alienate the users' experiences. Still according to the same authors, increased autonomy gained through choice could also better account for the heterogeneous needs and preferences of people. This view has inherent to it a recognition of the diversity of care, and has also obvious contact points with the feminist critique of the monolithic view of the welfare state as seen through the lens of a white, male, breadwinner and non-disabled perspective.

The issue of autonomy pertains very much with the notions of independence as the ability to make and not only implement decisions, i.e. the distinction between “decisional” and “executorial autonomy” as defined by Collopy (1995) and later Boyle (2005). While dependency in old-age may be related to a diminishing ability to operationalize decisions, it should not necessarily come with a reduced ability to make decisions regarding one's own welfare.

It was mentioned earlier (section 2.2.1) how care can be approached as a power relationship built on asymmetries and mutual dependencies between the carer and the person in need of care and how this is central in Kittay's (1999; cited by Fine 2007, p.68ff) work on care. Being

dependent on others to function creates vulnerabilities in the person in need of care and in this sense choice over the more intimate dealings of caring – the dimensions *from whom, what, how and when* in Table 2.1 – can be seen as a way to restore or equalise the imbalances of power inherent to the caring relationship (Glendinning 2008).

It is worth contrasting here the issues raised by needs assessment in health care and in long-term care. The specific knowledge associated with health care and the training of medical staff allow GPs an information advantage over patients (this is part of Arrow's (1963) seminal argument on asymmetric information in health care) and needs assessment becomes a principal-agent problem. In long-term care however, needs are not exclusively or necessarily linked to a health condition as dependency may also be a social construct. Particularly when user satisfaction is seen as a source of expertise and human relations as an outcome of care, it is not clear that users of long-term care are in the same unfavourable position to judge quality of care as patients are in relation to medical doctors in health care. Users of long-term care may thus come closer to the notion of expert patients referred by Greener (2007) in relation to those who are chronically ill.

Finally, choice and control are increasingly being seen as outcomes and dimensions of the caring process that are valued by those in need of care (Glendinning 2008). Research has found that choice and control over everyday aspects of care are fundamental for the quality of life of those receiving care (see Kane 2003; Davies 2001; National Care Homes Research and Development 2007 for some of the more recent reviews). Although this research has focused on residential care settings, there is no reason to believe that its findings cannot be generalised to those receiving care at home. Choice as an outcome of care is all the more pertinent given Baldock's (1997) concept of the user as co-producer of care.

The appeal of the consumerism rhetoric is evident, and is furthermore backed by the users' rights movement. It nonetheless raises pertinent questions regarding its suitability in the context of public welfare services in general and long-term care in particular.

Limits to the consumerism discourse

The notion that choice in long-term care has a positive intrinsic value is not without controversy and it has been questioned under two main arguments: a more pragmatic one, as choice can have potentially negative outcomes (i.e. choice entails a negative intrinsic value); and a more conceptual argument built around the inherent tensions that choice causes in the context of public services.

Taking the pragmatic criticism first, Le Grand (2007, pp.48–54) presents several examples that serve as testimony. In his view, the majority of people want to have choice and this is far from being a simple “middle class obsession” as poorer people are especially in favour of it. Green (2006, p.131) counter argues that what people say they wish in hypothetical situations typical of polls and what they want or need are two different things, for choice comes with costs.

Based on a series of behavioural experiments, Schwartz demonstrates that an excessively large pool of possibilities of choice could actually cause dissatisfaction or lead people not to exert choice at all, because it means more time is spent in the process and an increased chance of making the wrong decision and thus bearing increased costs of regret (Schwartz 2004). Decisions involving trade-offs are likely to be particularly susceptible to generate negative emotions during the process of choosing (Beresford & Sloper 2008). Downing and John (2009) label these as the psychological costs of choice, but they also referred to other costs such as when exerting choice actually produces a net welfare loss (e.g. making wrong decisions about subscribing complex long-term care insurance may put more people in need of scarce state support). Furthermore, the psychological costs of choice might be heightened in the context of long-term care where decision-making is often carried out under the influence of negative emotions or states of mind (e.g. stress, worry, anger), which means that the process of choosing may actually not be entirely enjoyable, even if the results of choice are positive (Baxter & Glendinning 2013).

The costs associated with choice (e.g. gathering and processing information) could still be bearable in the case of a one-off event. However, as Glendinning (2008) correctly stresses, long-term care is likely to be an on-going process of managing relationships with carers and formal provider organisations, involving: changing needs, where information gathered quickly becomes obsolete, negotiations with providers grow to be a repeated necessity, possibilities to reverse past decisions dwindle and uncertainty over the future is vast. All this can make the exercise of choice a rather negative experience, particularly for some groups of people, such as those with limited social networks on which to rely on. Clarke, Smith and Vidler (2005, p.176) on the other hand warn about “talking of public services as though their receipt is an unalloyed blessing, actively sought by its recipients”. This warning could certainly apply to long-term care, where demand is derived from the need of care. Choice could thus be experienced by some users more as an involuntary decision in the face of a process of physical or cognitive decline.

While the above criticism focuses on the workings of choice on an individual level, several other authors have raised more conceptual questions about the application of choice to public services (Jordan 2005; Clarke 2006; Clarke et al. 2005; Clarke et al. 2006; Clarke et al. 2007; Green 2006; Needham 2006; Greener 2007; Glendinning 2008; Powell et al. 2010; Stevens et al. 2011 are among the most recent). As Powell et al. (2010) rightly state, the concerns voiced by these scholars build on previous work by such authors as Marshall (1963), Robson (1976; as cited in Powell et al. 2010) and Titmuss (1968) who raised questions about how compatible choice is with the special characteristic that public services possess. These more conceptual questions can be arguably clustered around three issues or tensions:

- i. Tensions regarding the collective nature of public services and the private nature of choice.
- ii. Tensions regarding issues of power and knowledge.
- iii. Tensions around the management of risk.

The first of these tensions relates directly to Marshall (1963), Titmuss (1968) and Robson's (1976) early criticisms based on the particularities of public services. The idea is summarised in the statement by Clarke, Newman and Westmarland (2007, p.251) that "treating public services as though they are simply transactions misses many aspects of what makes them public". For Jordan (2005), social services are the product of an historical process that sought to foster a more managed social environment by providing collective protection against social risks and thus reinforcing the values of social justice and solidarity. Furthermore, they are also fundamental to build *social capital*, i.e. values such as trust, reciprocity and cooperation. The disconnection is thus between choice that aims to satisfy individual wants and the collective aims that preside over public services (Needham 2006). By focusing on outcomes and pitting the interest of users against those of providers or public officials, choice runs the risk of eroding the "public ethos" of these services (Needham 2006). This has similarities with Frey's (1998) theory of crowding out intrinsic motivations and Le Grand's (2003) concepts of knights and knaves.

Going back to Eika's (2009) point on the limited sovereignty of long-term care users and how relatives or friends could act as their representatives in the process of choice, Glendinning (2008) further questions how appropriate it is to take an atomised version of choice when even in the private household sphere decisions may be taken collectively. According to the same author, the interests of family carers and users can be seen as being simultaneously contradictory (e.g. mediating the contact between their dependent relatives and providers

may represent an extra burden on family carers) and juxtaposing (e.g. the wellbeing of carers may be dependent on the wellbeing of their relatives), in line with the interdependencies that are established in a caring relationship. In such situations, choice may well be better represented by alternative formulations that depict choice also as a product of the social context and shaped by social norms and values, in line with Granovetter's (1985) concept of socially embedded choice (Lunt et al. 1996; Fotaki et al. 2005). This is also in line with Jochimsen's (2003) aforementioned point about the role that social values and norms may have on the decision to enter and exit a caring relationship.

Another stream of thought anchored around the first tension identified above is linked to the fact that public services seek to address needs that usually exceed available resources, particularly in countries where long-term care is subject to means testing. Several authors have pointed to the contradictions inherent to the consumerist discourse, that promises the fulfilment of individual wants and needs and the several forms of rationing that are in use in social services, be it gate-keeping through professional needs assessment, waiting lists or other forms of collectively established priorities (Clarke 2006; Clarke et al. 2007; Arksey & Glendinning 2008). This holds even for long-term care systems based on social insurance rather than means tests (e.g. Germany). For Oliver and Evans (2005), this reflects a wider conflict between an individualistic concept such as choice and the collective nature of public services, which must concern itself with goals such as equity. The same authors argue that users are ill-equipped to understand and manage the broader resource constraints. Applying choice to long-term care could therefore at the very least run the risk of increasing users' expectations beyond what public resources can meet (Clarke 2006). In an interesting paradox, considering the context of financial constraints that surrounded the introduction of choice in some countries (Blomqvist 2004), Needham (2006) concludes that if public services were to be allocated through choice, this would most likely require surplus capacity as well as an expansion of services and public resources devoted to long-term care.

The compatibility of choice with rationing in long-term care is very closely related to issues of power and knowledge (Clarke 2006; Powell et al. 2010; Stevens et al. 2011). In traditional public services, bureaucrats have held considerable discretionary power over users as professional forms of knowledge were deemed essential to "discover", "confirm" or "legitimise" people's needs (Clarke et al. 2007, p.250). This was viewed as a source of subordination, dependency and reproduction of inequalities based on prejudice or discrimination (Needham 2006; Clarke et al. 2007; Stevens et al. 2011). To counteract this, some have argued for new forms of knowledge based on users' experience and satisfaction to

be recognised (Clarke 2006; Powell et al. 2010). Consumerism thus came to imply or at least hold the promise that people should be able to assess their own needs. Other, more sceptical authors (Clarke 2006; Clarke et al. 2007), wonder instead just how choice will make it any easier to respond to pressing questions such as who decides about priorities and allocation of resources.

Finally, the consumerist discourse is also contested on the basis of the tensions it creates over the management of risks (Glendinning 2008; Stevens et al. 2011). The discourse around choice depicts people as “self-governing social agents” (Green 2006) being able to “design their own social policies” (Klein & Millar 1995). While users may value the added flexibility that choice mechanisms, particularly cash benefits, provide them with, these also mean a profound shift in the management of risk (Glendinning 2008) – one that users or authorities may not be willing to do or feel totally comfortable with. From the users’ perspective, this could mean added stress and insecurity as they are called upon to become responsible for managing their own needs, wants and resources, or what Clarke, Smith and Vidler (2006, p.332) termed the “devolution of responsibility”.

Stevens et al. (2011) warn that authorities may question the “legitimacy” of certain choices made by users and to what extent they conform with collectively decided aims and views about what is deemed as an acceptable use of public benefits in long-term care. Their argument points to the strong social and policy constraints that may shape not only individual decision on the part of users (the argument used before by Granovetter (1985) among others), but also the design of choice policies themselves as “choice is seen to be firmly placed within the public gaze and potentially constrained by the power underpinning the public concern” (Stevens et al. 2011, p.268).

2.4 CONCLUSIONS

The introduction of user choice has been one of the most transformative developments in the way long-term care services are provided and allocated in Europe in recent decades. The appeal of user choice rests on what choice can deliver (i.e. its instrumental value) as well as its intrinsic value. Choice can make long-term care provision more efficient by wedding out low performing providers from the market. It can also improve how long-term care meets users’ needs by steering supply to the real needs and preferences of users (i.e. improving allocative efficiency), instead of responding to the directives of bureau professionals. In this narrative, users play a fundamental role. They push the levers of the market by entering and

exiting relationships with providers, i.e. by acting just like any rational consumer in a service market.

This view however, is not uncontroversial and this chapter reviewed many arguments why users of long-term care services may not act like the typical consumer. For example, users might not possess sufficient information to make choices. They might be unable to make choices even if all information is available, as in the case of users with dementia. Furthermore, people tend to make choices in a different way than that envisioned by economic models: using rules of thumb rather than weighing in the available evidence, being more fearful of losing what they have than gaining more (risk aversion), or being motivated by altruism and feelings of concern for others rather than individual self-interest. Lastly, choice is only possible if there are options to choose from.

Beyond the limits of the rational consumer construct that underpins much of the controversies surrounding user choice, this chapter also reviewed the characteristics of the markets in which care is bought and sold, as well as the characteristics of care that make it different from other commodities.

Concerning markets, there are a number of ways in which long-term care markets deviate from conventional markets. For example, prices paid by most users do not reflect the costs that providers incur to deliver care. These markets have therefore been denominated as quasi-markets. They are characterised by a strong state intervention due to legitimate concerns about what are usually referred as market failures, i.e. situations where markets produce outcomes that are not the best from the society's viewpoint. State intervention in quasi-markets also reflects concerns about the ability of those most in need of care to afford the care they need.

Even if strongly regulated, quasi-markets still entail transactions with users buying care from providers. While many would state that long-term care is just another commodity being sold and purchased at any given price, this chapter has highlighted important ways in which long-term care might differ from other commodities.

Arguably the most salient *difference* between care and other commodities is that care is not only comprised of tasks, *caring for*, but also involves feelings of concern, *caring about*. To put it in another way, care also involves a relational component. While there might be some disagreement as to the nature of this relationship – based on the dependency between the person cared for and the carer, or defined as an interdependent relationship – many authors

surveyed in this chapter nonetheless seem to agree that caring entails the establishment of a relationship between the carer and the person cared for. Besides this, another important *difference* lies in the fact that care also has a moral dimension attached to it. This is evident in the motivations underlying care provision. Many carers provide care because they feel it is the “right thing to do” even if this does not necessarily correspond to their own best interest. Finally, another salient *difference* regarding care is that it is a co-produced commodity. In order for someone to receive care, this person must accept and cooperate in the provision of care. How care is experienced by the user therefore depends on how the user engages with both the care giver and the care received.

Despite the prominence of the concept of caring as a relationship in the sociological literature, there has been scarce empirical research on its salience and limited discussion on the consequences of this concept for the application of competition and choice, as well as for state intervention in long-term care. Yet, if care does indeed have a relational component, this carries important implications. Firstly, it means that care is an *experience good* – one whose quality can only be ascertained after consumption takes place – not only in light of how tasks are provided, but also regarding how the relationship with the carer might be. This has the potential to further exacerbate the real issues around imperfect information that affect long-term care and provide one of the strongest arguments for state intervention. The latter may also be fundamental to addressing the potential asymmetric nature of caring relationships or to allow for those same caring relationships to develop (care as a citizenship right).

Secondly, if care has an attached relational component, then *from whom* care is provided, i.e. the identity of the carer, could be an important dimension of choice and determinant of satisfaction with care. The issues around imperfect information debated above may play an important role in the process of searching for and choosing carers. Furthermore, as the user is also a co-producer of care with idiosyncratic care needs and preferences over *what* and *how* to receive care, this means that the nature of the carer-user dyad (i.e. the relationship between the two) might also impact *how* care is provided and through that how users experience care.

Finally, the salience of relationships in the context of care could imply that decisions regarding care may not always follow a strict economic rationale, but be coloured by other motivations. In other words, if caring does have a relational aspect, this could impact on the decisions of users in their capacity as consumers of care.

This chapter has argued that in order to understand choices made by users of care, it is necessary to discuss the characteristics of care as a commodity, and in particular, whether it comprises a relational dimension and whether this impacts on the choices of users in their capacity as consumers of care. However, the social policy and economic theoretical literature as well as the empirical research have neglected the special relationship aspects of long-term care that make it different from ordinary consumer services. This thesis will therefore seek to fill this gap. As discussed in this chapter, this carries implications both for the application of competition and choice in long-term care and for the arguments justifying state intervention in long-term care. For this purpose, it will rely on the example of one country, which was at the forefront of the introduction of competition and user choice from the early 1990s: England. The next chapter will chart the implementation process and outcomes of quasi-markets (i.e. competition) and choice in England. Understanding this process is a necessary pre-condition to empirically test the relevance of the relational aspects of care in the choices of users of care.

Chapter 3 : REVIEW OF USER CHOICE POLICIES IN LONG-TERM CARE IN ENGLAND

Providing users with the possibility to choose has been one of the drivers of reform in European long-term care systems as part of the broader trend towards relying more on market mechanisms for the provision of care, which the quasi-markets alluded to in the previous chapter are an example of (Timonen et al. 2006; Pavolini & Ranci 2008; OECD 2005). These user choice policies, however, have been quite diverse both between and also within countries. This reflects not only different national policy contexts, but also different aims that the user choice policies have sought to accomplish beyond bringing about *enhanced autonomy, empowerment and freedom* (Da Roit & Le Bihan 2010). For example while in countries such as Austria and Germany user choice policies were meant to support informal care and included the introduction of cash benefits provided to those in need of care, in Sweden concerns about efficiency dominated the implementation of quasi-markets in long-term care, which for the most part did not include a relevant role for cash benefits (Ungerson & Yeandle 2007; Da Roit & Le Bihan 2010).

In the previous chapter, choice was defined around 6 dimensions following Le Grand (2007): agency (i.e. who is empowered to choose) and choice over where, from whom, when, how and what (see Table 2.1 in Chapter 2). Starting from these dimensions, it is possible to group the several national approaches to user choice and competition under three broad types, which are depicted in Table 3.1 (Ungerson 2003; Lundsgaard 2005; Glendinning & Kemp 2006; Timonen et al. 2006; Colombo et al. 2011; OECD 2005; Ungerson & Yeandle 2007; Da Roit et al. 2007; Da Roit & Le Bihan 2010; Bode et al. 2011). These include i) institutional consumerism, in which the functions of purchasing and provision are separated, and agency rests mainly with the public purchasing authority; ii) regulated cash benefits, that provide those in need of care with a budget (voucher) that can be used to acquire pre-determined types of care from an agency or to employ a personal assistant; and iii) de-regulated cash benefits, which allow those taking-up the benefit to spend it as they wish so long as sufficient care is secured. The lower end of Table 3.1 depicts the dimensions of choice allowed from the perspective of the user under each type of user choice mechanisms. While there is an implicit broadening of the scope for choice as one moves from institutional consumerism to de-regulated cash benefits, the regulations governing vouchers may place this type of user choice closer to one of either of the other typologies – for example, depending on who is allowed to determine the contents of the care package.

Table 3.1 – Typology of user choice mechanisms in long-term care in Europe

	Institutional consumerism (e.g. purchaser-provider split)	Regulated cash benefits (e.g. voucher)	Deregulated cash benefit
Description	Once eligibility has been determined, the decision to purchase care (agency) rests mainly with the public authority although the user may express his/her preference. Decision to purchase is independent of producing care and different provider organisations may compete in the market.	Benefits are provided in terms of a budget or voucher that can be redeemed for a certain number of hours of care provided by a formal provider organisation; alternatively the benefit can be used to employ a personal carer (often including relatives but with restrictions on close relatives), in which case the relation between the user and the carer must be formalised (e.g. through an employment contract).	Benefits take the form of cash that can be used to buy hours of care services, employ a personal carer or compensate relatives (including close ones) for the care provided (<i>routed wages</i>). Although authorities assess if sufficient care has been secured, no proof of expenditure or employment contract is required and use of benefit is at the user's discretion. Benefit paid to the carer is rarely taxed in the context of care provided within the family.
Examples of countries (benefit)	England (Personal Budget managed by Local Authorities), Sweden, Norway	Germany (institutional and home care services), England (Personal Budget taken as a Direct Payment), France, the Netherlands, Sweden, Denmark, Finland.	Austria, Italy, Germany (cash option)
Dimensions of choice allowed (user)	Limited choice over formal provider organisation (i.e. only from the pool of organisations contracted) and only indirectly over <i>what, how</i> and <i>when</i> care may be delivered.	Agency rests with the user, choice over <i>from whom</i> care is received and to some extent <i>when</i> ; control over contents of care (<i>what</i>) varies between national schemes	Agency rests with the user, choice over <i>from whom</i> care is received, <i>when, how</i> and <i>what</i> care is received.

Source: Author's compilation.

The United Kingdom, and in particular England, was at the forefront of the implementation of user choice policies and competition. This was driven by two movements that have often been mutually enforcing, albeit both from rather different ideological backgrounds and each pursuing its own separate agenda. On the one hand, the fight for more independence and control by disabled rights movements, and on the other hand the quest for more efficient social services grounded on New Public Management (NPM) theories of public governance (Hardy & Wistow 1998; Glendinning 2008). Starting with institutional consumerism in the 1990s, elements of user choice were gradually introduced and expanded in the following

decades, culminating in the current Personal Budgets – a form of regulated cash benefits operating alongside non-negligible institutional consumerism, especially for older people.

Before depicting the current user choice policies based on Personal Budgets (PB), as well as assessing their outcomes for older people, it seems salient to look at the path that led to the current arrangement. The current user choice policies in place in England reflect successive debates and reforms in the past 20 years. Succinctly revisiting those debates and reforms will provide a better insight into the characteristics of the current system. Furthermore, past reforms and policy options in terms of user choice have in practice shaped the landscape of care within which PBs now operate. These are thus crucial to understand its outcomes and limitations, i.e. there is an element of path dependency that is important to acknowledge. It is also important to refer upfront that the debates and reforms reviewed here took place against a backdrop of increasing pressures to limit public expenditure on the one hand, and increasing demand for long-term care due to population ageing on the other hand (Glendinning 2008). It is important to bear both of these constraints in mind to understand not only the evolution of competition and user choice policies in England, but also their introduction in the first place.

The structure of this chapter mostly reflects the chronological sequence of events. The first section is centred on the implementation of quasi-markets in England that operated through institutional consumerism. Although quasi-markets were implemented in long-term care in 1993, the narrative begins some years before to summarise the main arguments that led to the introduction of quasi-markets. The second section is centred on the subsequent developments and elaboration of quasi-markets with successive measures to devolve agency to end users of care. Picking up on arguments from the disability rights movement that date back to the 1970s, this second section covers the period from 1997 to the present day. In the third and final section, a critical assessment of the introduction of user choice and competition in long-term care in England is presented.

Finally, two notes on the scope of this review. Firstly, given the devolution system in the United Kingdom, its countries have considerable leeway in defining and implementing long-term care policies and their experiences have indeed been heterogeneous. This review of user choice policies therefore focuses on the experience of England. Secondly, the focus of this review is on care provided to older people in their own home, from here onwards referred to as home care. Home care is meant to include both personal care (e.g. help with bathing) and domestic care (e.g. cleaning services). Unless clearly stated otherwise, in the

context of this review, home care does not include other forms of non-institutional care, such as day care or respite care.

3.1 INSTITUTIONAL CONSUMERISM AND QUASI-MARKETS

The provision of long-term care in post-war England had traditionally rested on in-kind benefits, with Local Authorities (LAs) barred from providing cash payments to disabled people, and a strong emphasis on the role of professionals as gatekeepers to care benefits (Glendinning 2008). Under this institutional arrangement, the state, through the LAs, retained the prominent role as both funder and provider of care services in long-term care, as it did in other areas of social policy (Stevens et al. 2011; Means 2012).

In the early 1980s, however, this *status quo* came under increasing pressure. Public expenditure on institutional care was soaring as a result of funding rules that allowed low income people to choose a private nursing or care home and claim all expenses from the social security budget (Lewis & Glennerster 1996). A report by the Audit Commission (1986) exposed the costs incurred with what was in fact a voucher system and its contradiction with the government's stated aim of enabling people to be cared for in their homes.

The remedy came in the form of a series of proposals contained in the denominated *Griffiths Report* (1988). The Griffiths Report called for halting the social security payments for institutional care, and for the creation of quasi-markets in long-term care, with a prominent role to be played by community care (i.e. non-institutional care) and the denominated *independent sector* (i.e. non-public formal providers). The recommendations contained in the Griffiths Report reflected the mood of the times. During the Thatcher governments, NPM ideas based on contractual transparency, monitoring and performance indicators, competition and incentives had gained prominence, and became the advocated basis for the process of reform of public social services that were deemed both unresponsive to users' needs and inefficient and costly to the public purse (Le Grand & Bartlett 1993). Introducing choice and competition would make services more responsive to users' preferences and raise quality while reducing costs, as echoed in the Griffiths Report (1988).

The 1990 *National Health Service (NHS) and Community Care Act* was the embodiment of this rationale. When it came into effect in 1993, it established quasi-markets for long-term care, as well as for health care, that sought to expose public providers to competition from private providers, also denominated *independent providers* (for-profit and non-profit). The aim was

also to restrict public expenditure on institutional care whilst channelling public expenditure to develop home care (Glendinning 2012).

The social security payments for board and lodging had fostered the creation of multiple small scale private providers of residential care, which the Thatcher government sought to protect. For this purpose it stipulated that 85 per cent of the *community care special grant* diverted from the social assistance budget to LAs to develop quasi-markets was to be spent on the independent sector (Lewis & Glennerster 1996, p.9). Nonetheless, up until the creation of quasi-markets, independent providers of domiciliary and community care services had historically played a more subsidiary role in England than in countries such as Austria or Germany. It was only in institutional care that independent providers had some clout. This meant that in many regions the *mixed economy of care* – i.e. competition on the same footing between different types of formal providers that was central to the introduction of quasi-markets – had to be promoted, particularly in community care (Hardy & Wistow 1998). In line with NPM theories, purchasing and provider functions that until then had both been held by LAs, were separated, and public services had to compete with private formal provider organisations for the provision of care services commissioned by LAs. LAs were therefore to change their role from “provider” to “enabler” of care by becoming commissioners and purchasers of care (Hardy & Wistow 1998).

At the same time, care managers¹⁵ employed by LAs were entrusted with assessing needs and eligibility for care services, as well as assembling and purchasing a care package from the formal provider organisations contracted by the LA. In acting like gatekeepers to access care¹⁶, care managers were thus essential to optimise the use of services and to bring about the efficiency gains that were at the heart of the aims of the reform. This reflected earlier experiments with case management in the Thanet area in Kent that had proven successful in retaining older people in their homes by coordinating community care services (Challis & Davies 1986).

With the 1993 reforms, although care managers were entrusted with purchasing care on behalf of users, they seldom held devolved budgets – unlike the earlier case management experience described above. Instead the reform emphasised their gate-keeping role in

¹⁵ The generic term “care manager” is used as a convenience to cover an array of job titles in LAs that dealt with assessing both eligibility and commissioning care services.

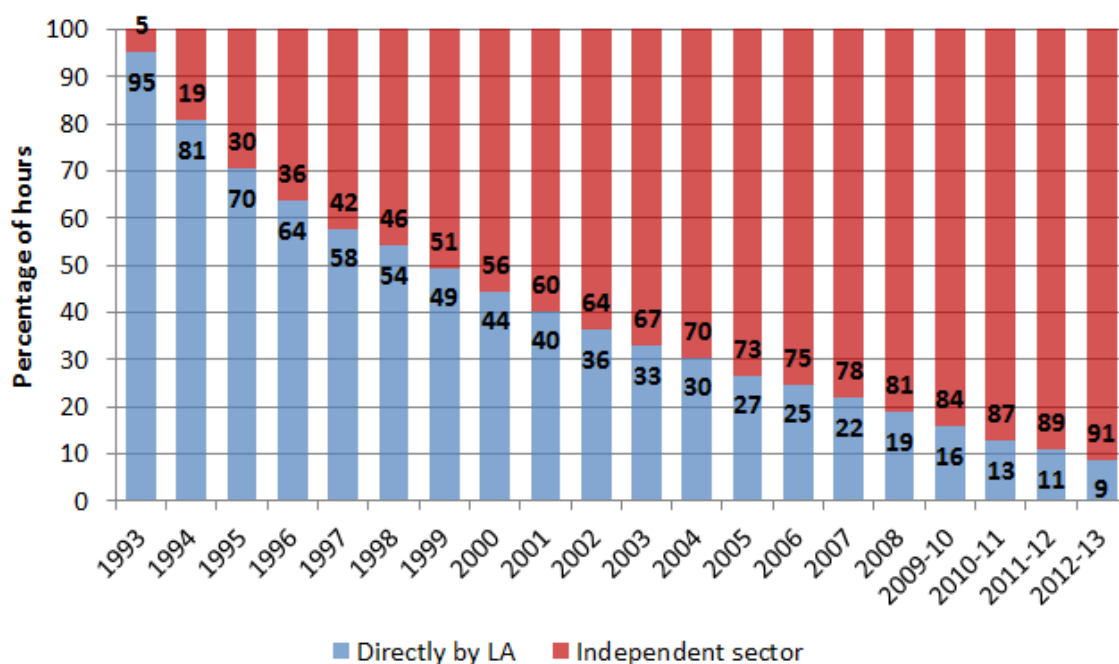
¹⁶ Previously, users had only been able to enter institutional care on the basis of their low income.

limiting access if not demand and thus costs (Lewis & Glennerster 1996; Jacobs et al. 2009). LAs thus became monopsonic buyers of care which gave them a fairly large degree of market power in determining prices. Further efficiency gains were expected from care managers possessing a good knowledge of local markets that would enable them to coordinate and put together tailor-made and value for money care packages (Glendinning 2008). Although the introduction of quasi-markets assigned lead responsibility for community care services to LAs, it did not change the means-tested nature of the English long-term care system, nor did it change the fact that cost-containment in relation to spending on institutional care was one of the main aims of the reform (Lewis & Glennerster 1996).

The creation of quasi-markets in long-term care had a profound impact on how care was provided and on users' experiences with care. Each of these transformations is now described in turn, starting with the former.

Senior responsible officers from the LAs initially voiced concerns about the *different nature of long-term care* and their suspicions about the adequacy of market mechanisms to supply care, as well as the ability of for-profit providers to supply quality care (Hardy & Wistow 1998). Despite these reservations, within the home care sector the LAs steadily and increasingly contracted services from independent formal provider organisations, albeit at a slower pace than in residential care where a more sizeable private market had already been in place prior to the *1990 NHS and Community Care Act*. Just before the implementation of quasi-markets, only 5% of care (hours) provided at home was delivered by the independent sector, while in 2012-13 the figure was 91% - Figure 3.1.

Figure 3.1 – Evolution of care hours provided, by type of formal provider organisations



Source: Own calculations based on NHS Information Centre (2006; 2009) and Adult Social Care Statistics (2013)

Notes: There is a break in series in 2008/09. Until 2008 data refer to distribution of hours on survey week in September, whilst from 2009 onwards data refer to total number of hours provided.

Although the independent sector grew rapidly – thus fulfilling one of the aims of the *1990 NHS and Community Care Act* – Hardy and Wistow (1998) refer to a fragmented community care sector, dominated by small size agencies utterly dependent on LAs for most of their business, facing not only downward price pressures from monopsonic LAs purchasers, but also precarious revenue streams arising from contracting practices from LAs. Spot contracts, which offer no guaranteed price or quantity until the actual time of purchase, or *call-off* agreements, where price and general conditions are agreed in advance but quantity is not defined, were the preferred form of contracting by LAs in the years immediately following the introduction of quasi-markets (Hardy & Wistow 1998; Knapp et al. 2001; Ware et al. 2001). At the same time, however, spot contracts were also more likely to allow for the kind of free choice of home care agencies that had been at the heart of the new legislation (Mannion & Smith 1997). With time, and continuing tightening of budgets, LAs’ contracting practices in community care evolved to offer greater stability at lower costs. One example is through the use of block contracts that guaranteed (discount) prices and quantities of care to be

purchased. Another is zoning practices, which gave some home care agencies preference within a given geographical area and thus helped to increase efficiency in the delivery of care by reducing travel costs (Ware et al. 2001; Forder et al. 2004; Baxter et al. 2011).

As early as 2000, there were emerging signs that the independent sector was becoming more concentrated through a series of mergers of small home care agencies (Ware et al. 2001). Here, it is worth briefly contrasting the reality of the home care market, with that of residential care. The latter eventually evolved to become more concentrated and less reliant on LAs for funding, in part given the higher share of users self-funding their care (Baxter et al. 2011).

From the user's viewpoint, the *NHS and Community Care Act 1990* and accompanying guidelines for implementation, stipulated that users would be assessed, a care package would then be assembled, after which the user could eventually express preference for a given formal provider (i.e. a home care agency). The institutional consumerism rationale, however, placed the purchasing choice very much in the hands of care managers. The actual involvement of users in the whole choice process, namely in assessing their needs, can best be summarised instead by the finding that "users and carers (...) tended to think they had been 'consulted' rather than 'involved' in decision making" (Hardy et al. 1999, p.487), which was hardly an isolated case found in the literature on the topic (cf. Smith et al. 1995 ; as cited by Hardy et al. 1999, p.487; Knapp et al. 2001; Jacobs et al. 2009). Reasons for this were complex, ranging from over-zealous care managers concerned with the vulnerability of old-age users and their ability to act as consumers of care (Hardy & Wistow 1998), to lack of information and real empowerment. The conjugation of these elements only reinforced passive attitudes of users and relatives that were either happy to have others making the decisions for them – an example of Thaler's (1980) cost of regret trumping choice – or just glad to receive something (Hardy et al. 1999; Ware et al. 2003).

Commissioning practices also had an impact on choice experienced by users. As cost constraints faced by LAs grew, these not only tightened eligibility to increasingly frail older people, but gradually came to fund only personal care. Downward pressure on prices paid by LAs, reliance on spot contracting, and the fact that LAs did not pay for travel costs, impacted the workforce by making it more difficult to assure a steady workflow of staff. It also proved difficult to guarantee continuity of care due to staff turnover (Hardy & Wistow 1998; Hardy et al. 1999; Ware et al. 2003; Wilberforce et al. 2011). Hinting at the importance of the relational aspects of care, older people often expressed stronger views not so much over the choice (or lack) of formal provider organisations (i.e. home care agency), but over the identity of their

carer(s) (Smith et al. 1995; Hardy et al. 1999). Finally, care managers were often too prescriptive regarding the contents of the care package and even small changes would require renegotiations between home care agencies and care managers.

In conclusion, profound changes were triggered by the introduction of quasi-markets, not least the introduction of competition and choice (Le Grand 1991a; Le Grand & Bartlett 1993). Regarding the latter however, the reforms introduced in 1993 placed the decision to choose in the hands of LA care managers, with users only nominally entitled to express their preferences. The reforms introduced in 1993 can be credited with increasing competition in the care sector as well as creating a mixed economy of care provision; however, the outcomes in terms of greater choice for the user (i.e. *user choice*) were decisively contentious. A greater emphasis was placed on competition rather than on empowering users with choice. User choice, particularly over other dimensions such as *what*, *when* and *from whom* (identity of the carer) was either limited or non-existent. It is perhaps important to go back to the previously referred Klein and Millar's (1995) concepts of *choice that is allowed*, *capacities for choice* and *choice set* and Le Grand's (2007) *dimensions of choice* (see section 2.3.1) to place choice under quasi-markets into perspective. At best, it can be argued that through competition, quasi-markets allowed users a wider *choice set*, i.e. more formal provider organisations from which to choose from. However even this is contentious as users remained at arm's length in the process of choosing home care agencies and choices were limited to only one of the dimensions of care depicted in Table 2.1 in Chapter 2. As described above, *allowed choice* remained limited only to formal provider organisations that had contracts with the LA and as selected by care managers - this did not include choice over tasks or times for care. By not empowering users with agency, the *capacity to choose* was also curtailed and left firmly in the hands of care managers.

3.2 DELIVERING CHOICE TO USERS

As discussed above, the NPM-flavoured *1990 NHS and Community Care Act* sought to address calls for reform of a system that in the late 1980s was seen by many as expensive, inefficient and biased towards institutional care. These were not, however, the only calls for reforming the system. The disabled rights movement had long been campaigning for greater control and empowerment in the choice of care. As these arguments came to be harnessed by the Blair government in subsequent reforms of long-term care for older people from the mid-1990s onwards, it is worth to briefly summarise the campaign of disabled rights movement for greater control over their care.

The campaign waged by the disability rights movement to reform the long-term care system dates back to the 1970s. Disabled people argued with the state to give them control over the money spent on care so that they could use this to purchase the services and support they needed to live independently (Riddell et al. 2005). Well before quasi-markets, disabled people campaigned to change a system that they felt reinforced the subordination and dependency of users on “bureau professionals” (Scourfield 2005). They believed the care delivered was inflexible and task rather than user-oriented (Morris 1994; Kestenbaum 1993). The notion that “services should be tailored to the people that use them” (Needham 2011, p.54) was to become a central tenet of what came to be known as *personalization* of social care.

A number of smaller scale initiatives had been set up prior to the introduction of quasi-markets; disabled people were provided with cash which they could use to employ their own personal assistants. Chiefly among these was the Independent Living Fund (ILF). Set up in 1988, the ILF was a stop-gap response to changes in disability benefits legislation, which had threatened to abolish additional payments that could be received by severely disabled people to employ a carer and thus continue to live at home. Although confined to a small number of severely disabled people, the ILF highlighted the existence of unmet needs for care among disabled people (Henwood & Hudson 2007). The other initiative set up around the same time by a number of LAs were third-party payments to disabled people through third sector organisations, a move that allowed LAs to circumvent the ban on providing cash payments¹⁷. Finally, it is worth stressing that older people were for the most part excluded from these direct and indirect payment schemes and that the campaign for direct cash payments was mainly led by physically disabled people of working age.

It was clear that the creation of quasi-markets in long-term care focused more on the supply side of choice, by effectively creating a mixed economy for the provision of care, than on empowering users. The *delegated choice* arrangement inherent to institutional consumerism thus left unanswered the calls for greater empowerment and agency, underlying both the consumerism and disability rights discourse. Scourfield (2005, p.470) characterised the English social care system as being controlled by professionals whereby “The subordinated position of disabled people was underlined by a system which arranged services for them based on assessment and service availability”. Quasi-markets had done little to change this

¹⁷ English LAs had been barred from providing cash payments since the *1948 National Assistance Act*.

for disabled and older people alike and had only reinforced the power of professionals, i.e. they had left unchanged the power relations between users and professionals inherent to the construction of disability (Priestley et al. 2007). Care assessments were foremost a tool for rationing scarce supply and keeping costs down (Lewis & Glennerster 1996). Furthermore, as evidenced above, it remained contentious whether services were responding to users' needs and preferences.

Campaigning for cash payments by disabled people therefore continued, both on the grounds of the instrumental value of choice – hoping to bring about an increased responsiveness of services that remained inflexible (Morris 2006) in order to deliver care that fitted people's needs – as well as the intrinsic value of choice – with the ability to choose being tantamount to the autonomy, citizenship and quality of life (Glendinning 2008; Stevens et al. 2011). In times of cost-savvy policy-makers, it did not hurt that research proved cash benefits to be cost effective too (Zarb & Nadash 1994).

3.2.1 PROVIDING AGENCY, CASH AND AN OPT-OUT TO USERS – DIRECT PAYMENTS

When the *Community Care Act (Direct Payments) 1996* was implemented in 1997, it finally lifted the traditional prohibition on LAs to provide cash payments, although older people only became eligible to receive them from the year 2000. Corresponding to the demands from the disability rights movement, the *Community Care Act (Direct Payments) 1996* also enabled end users of care that received cash payments to have a degree of control over the care they received; this had been unheard of until then in England.

According to the new legislation, upon assessment of eligibility for LA-supported care, users were given the choice to receive a Direct Payment (DP) of cash of an amount equal to the value of the care services allocated and use this cash to purchase their own care. DPs not only gave users agency to make their own choice – which thus far only self-funded users were afforded to – but crucially it also gave them the possibility to use DPs to hire their own personal assistant (PA) or by purchasing care themselves from an agency. This could be done by either directly employing a PA or by using the services of a broker agency to manage payments and employment requirements while retaining responsibility for hiring and firing the PA¹⁸ or purchase care themselves from an agency. This addressed the issue of the personal nature of care. It was indeed an option valued by user-employers for the continuity,

¹⁸ These support services only developed gradually.

choice and control from whom they received care, as it has been amply demonstrated by research since (Dawson 2000; Glendinning, Rummery, et al. 2000; as cited by Scourfield 2005, p.478; Stainton & Boyce 2004; Arksey & Baxter 2012). DPs went as far as permitting relatives to be employed as PAs - albeit not close co-resident ones¹⁹ in the majority of cases. DPs thus allowed for an expansion of the dimensions of choice over which users had control: by directly employing PAs, users could have greater leeway not only over whom they received care from, but also in influencing how and when it was provided. Unlike de-regulated cash-benefits, however, strict accounting and proof of expenditure of DPs was requested from users, by requiring them to set up a dedicated bank account to manage the DP. Similarly, money could not be freely transferred within the family (e.g. to compensate care provided by a daughter or son). Choosing a PA normally entailed the establishment of an employment contract and the payment of taxes.

With the implementation of DPs in 1997, a very important step was taken towards providing users of care services with agency. As such DPs “provided a welcome focus on the needs of the individual as a mechanism for implementing changes in the care market” (Davey et al. 2007, p.117). Research showed that the opportunity to choose the carer, particularly one with whom they were already acquainted with, seemed to have been particularly valued by people from different user groups in terms of allowing for continuity of care and the possibility to build a rapport with the carer (Moran et al. 2013; Stainton & Boyce 2004). Furthermore, users also welcomed the greater leeway that hiring PAs afforded them in defining when and how care was provided. Very often this encompassed tasks that home care agencies had not been able to provide, or that were excluded from the care packages purchased by LAs, such as domestic chores (Arksey & Baxter 2012).

As mentioned above, DPs were initially restricted to disabled people of working age, but eligibility was extended to older people and parents or carers of disabled children in 2000. The discretionary nature of DPs was also replaced in 2003 by a statutory duty for LAs “to make direct payments to individuals who consent to and are able to manage, with or without assistance” (Department of Health 2005). To give further weight to this mandatory procedure, take-up of DPs became a performance indicator for LAs in 2003. These developments underlined the political commitment of policy-makers to DPs, but also testify

¹⁹ In 2007 regulations were amended and employment of co-residing relatives became possible at the LAs' discretion if that was deemed necessary for the user to secure access to care (Glasby & Littlechild 2009).

to the efforts needed to overcome one of the main characteristics of the implementation of DPs: their uneven take-up across user groups and LAs (Riddell et al. 2005; Davey et al. 2007; Fernández et al. 2007). In a survey made across different countries of the UK and different LAs, Davey et al. (2007) found take-up of DPs to be higher among physically disabled people. The latter had traditionally been at the forefront of the claim for cash benefits, while in comparison older people lagged behind. As this came to be an enduring feature of DPs – even after the introduction of Personal Budgets as will become evident in the next section – it is worth detailing the several explanations that have been advanced to account for this significant difference.

One line of reasoning linked lower take-up by older people to the over-zealous or outright discriminative attitudes of care managers. Care managers had traditionally been wary of providing cash to older people on account of their perceived vulnerability (Mannion & Smith 1997). By requiring that DPs should be given to those “willing and able” or with “capacity for consent and ability to manage”, enough room was left for local interpretations on who should be given the option to receive a DP, very often to the detriment of older users and people with mental health problems (Spandler & Vick 2005). Although many professionals viewed DPs as a challenge to their monopoly on decision-making (Ellis 2007), it is fair to say that their attitudes were not solely driven by professional prejudice, but resulted also from genuine concerns and anxiety over management of risk and on becoming liable for users’ poor choices (Scourfield 2005; Priestley et al. 2007). Conversely, when staff were engaged and knowledgeable about DPs, they could also be valuable champions for DP provision and take-up, as evidenced by the fact that LAs with higher take-up among physically disabled people, also had higher take-up among older people (Fernández et al. 2007).

Another explanation put forward linked lower take-up with the increased anxiety that DPs could cause. The ILF had showed how disabled people could benefit from the flexibility, control and continuity that came with choosing one’s carer (Kestenbaum 1992). The experience of searching for and employing a PA could nonetheless be quite unsettling for users, whenever sufficient information was not in place (Spandler & Vick 2005). As PAs remained largely an unregulated activity as far as training and qualifications were concerned, information on potential PA employees could be scarce and leave users vulnerable to abuse (Scourfield 2005). The possibility to hire someone previously known to users, such as friends and relatives including co-residing ones, was important for the sense of security of older people (Moran et al. 2013), but this option was not always available. Managing DPs could prove to be a daunting task, and not surprisingly LAs that had payroll support services in

place did better in terms of take-up of DPs (Priestley et al. 2007). Some of the evidence quoted here refers to the experiences of users other than older people, but it is fair to assume that many older users of DPs would relate to them as well. The lack of information regarding PAs and vulnerability to abuse were unfortunately as much present for older people, many of whom lived alone, as they were for disabled people of working age. Managing DPs could also prove difficult for isolated older people with reduced social networks, or those with limited access or expertise of using the internet.

Both the *Wanless Report* (2006) and Glendinning (2008) pointed towards another related factor impacting the take-up of DP by older people. Unlike disabled people of working age, older people's first contact with DPs often came during a crisis situation such as a family carer becoming ill or an imminent hospital discharge. During such times they were arguably more vulnerable and less able to both actively claim the benefit and make the necessary arrangements to secure care. At the point of assessment, older people might still be coping with new and unstable needs, making it more difficult to predict the support they need or take on increased responsibilities (Newbronner et al. 2011; Carr 2012; Arksey & Baxter 2012).

Finally, LA funded care was increasingly being targeted to those with higher needs, and DPs were no different (Davey et al. 2007). Frailer older people would be less likely to be deemed *willing and able* to manage DPs by care managers and could indeed experience greater difficulties in managing the DP themselves. As eligibility tightened – a trend that the introduction of DPs did not alter – older people using care were thus more likely to be frail, which in turn also made the above-mentioned crisis referrals more likely. The amounts provided to older people were also frequently smaller, which limited their choice and perhaps made it less worthy to go through the extra work of managing DPs (Clark et al. 2004).

Setting-up DP use as a performance target did seem to have had a positive impact on take-up rates (Priestley et al. 2007). Nonetheless, LAs continued to have great latitude on how to distribute and manage DPs and support services. LAs and frontline staff responsible for assessing and managing DPs remained all too aware of the tensions involved in the management of risk. They understood the delicate balance between empowering users and accounting for *good use* of public money, which often meant trading stricter audits over the use of DPs at the expense of greater flexibility in the use of the benefit (Stevens et al. 2011). Predominant welfare state culture remained rooted in the provision of services and suspicious of how users would use cash payments.

The fact remained, however, that take-up was lower among older users, in contrast with other countries. For example, in Germany, the cash option was preferred by older users, even if it meant a lower payment. In this case, it allowed them to pay relatives and thus maintain caring relationships of reciprocity and at the same time receive care that was closer to users' preferences and images of "good care", unlike care provided by agencies (Eichler & Pfau-Effinger 2009). Unlike DPs however, the cash payment option in Germany is relatively unregulated and can thus be used freely to pay relatives living in the same household without need of employment contracts – a feature reflecting one of the stated aims of the German cash benefit system to support informal care.

It seems clear that DPs were a step forward in increasing the choice that users were allowed to have, by providing users with agency and expanding the dimensions of choice over which they had control to include *from whom, how* and *when*. Nonetheless, DPs were more akin to an opt-out mechanism from traditional LA-commissioned care, used only by a minority of older people. Users remained mostly dependent on the assessment of what type of care to receive by a third party – care managers, although those using DPs to employ PAs had arguably more leeway to agree with carers on the type of care to receive.

The geographical and user group variation in take-up of DPs, however, also exposed the importance of users' capacity for choice, or being supported to choose (Klein & Millar 1995). The literature surveyed pointed towards the role that care managers continued to play as purchasers of care by creating an enabling environment for choice (e.g. by allowing users to choose DPs after their condition had stabilised). They were also key in providing sufficient and adequate information on DPs and defining the resources and care packages allocated to older users. Despite this, DPs did signal both a greater commitment to devolve choice to users as well as the take-up of consumerism principles by social policy under the Labour governments of the late 1990s and 2000s. It marked a move towards fulfilling the calls from the disability rights movement - particularly physically disabled people of working age - for greater empowerment and personalisation of care. Future reforms would build on this experience and DPs would continue to be available to older people in need of care. Paradoxically however, many of the issues identified above as hindering their take-up by older people would remain.

3.2.2 MAINSTREAMING USER CHOICE THROUGH PERSONAL BUDGETS

The introduction of DPs had pushed the boundaries of choice to give users control over the dimension *from whom, when* and *how* care was provided – at least for those opting for DPs.

With DPs, users had effectively been recognised as co-producers of care (Leadbetter 2004). For those that did not opt for DPs – and among older people these were the majority of users – it was still up to professionals to judge and sanction on their behalf which services were best suited to meet their needs. Moreover, the gatekeeping role remained firmly in the hands of professionals – and with time the services sanctioned by LAs had increasingly been limited to personal care – enabling them to influence take-up (cf. Spandler & Vick 2005; Ellis 2007). Users were often left with one option: to *vote with their feet* – i.e. exit – to influence the *what* dimension of choice and this only if they were able to manage DPs (Hardy et al. 1999). Concomitantly, LAs' increasingly tightened budgets translated into DPs of lower amount, which left little resources available to fund anything else but essential personal care needs. Finally, DPs only covered the social care component, leaving out other sources of funding for care, which could compound on the complexities of navigating the system of care benefits. It was against this backdrop that the Individual Budgets (IBs) experiment came to be implemented.

The proposal to experiment with IBs grew out of a series of policy documents in the mid-2000s, that sought to level the playing field for all groups of users to benefit from choice, and from the experience of the initiative *In Control* (Glendinning et al. 2008). Piloted by people with learning disabilities, *In Control* sought to personalise services by giving users greater leeway in the definition of their needs and means to satisfy them (Poll et al. 2006). This meant not only employing PAs or purchasing services directly from home care agencies, which the DPs already allowed for, but also paying relatives or friends or alternatively purchasing mainstream activities such as social outings. This vision was reflected in official policy documents, among these chiefly was the Report *Improving the Life Chances of Disabled People*, which detailed the vision of how “individualised budgets” would pull together different funding sources to help meet the goal of independent living:

Disabled people – and the families of disabled children – should be able to choose whether they take their individualised budget in cash, in some combination of services and cash payments, or entirely as services commissioned by their local authority. The budgets should be used to get whatever type of support the individual needs. (Prime Minister's Strategy Unit 2005, p.13).

Following the principles of the *In Control* initiative, IBs were going to represent a fundamental shift in the delivery of care in five key areas, as laid out in *Improving the Life Chances of Disabled People*:

- i. Funding: unlike DPs, IBs gathered funding from different sources and benefits into one budget, thus rationalising the number of assessments and reviews. On this premise alone, IBs should prove easier to navigate than DPs.
- ii. Assessment: the process of assessing one's needs was meant to become more akin to a self-assessment procedure led by users with support from care managers, with the amount of the IB reflecting relative need calculated by a standardised resource allocation system (RAS). Users were encouraged to define the outcomes and how the IB could best accomplish them.
- iii. Use: users would be provided with greater latitude and flexibility to use their IBs in novel ways: not only could IBs be used to hire PAs (which was possible already with the DPs), they could be spent on mainstream activities and services, such as paying for social outings, and not just day care. This reflected one of the hard-core principles of the *In Control* initiative (Duffy 2004) and the personalization agenda (Needham 2011).
- iv. Deployment: IBs could be received as a cash payment – in which case they would be denominated as DP – to be managed directly by users to purchase their own services or employ a PA; they could be held and managed by the LA on behalf of the user; they could be held and managed by a third party, such as a relative or a formal provider; or through a combination of any of the above options. A user could decide to have part of its IB managed by the LA and take the remaining as a DP to employ a PA, or pay for social outings.
- v. Scope: although the Report clearly stipulated the need to pilot this new approach, it was clear that, if successful, IBs were not meant to be an opt-out, as DPs had been in the past. They were to become the standard way of delivering publicly funded non-institutional care.

Between 2006 and 2008, the IBs were piloted in thirteen LAs, of which eight provided IBs also to older people (see Glendinning et al. 2008 for details on the evaluation and setting up of the pilots), but midway through the IB pilot process the government decided to mainstream the benefit, now re coined as Personal Budget (PB), and to extend it nationwide albeit including only social care funding. Subsequently, PBs were to become the cornerstone of community care²⁰ in England as LA-supported care was to be provided through PBs to all new users from April 2011. PBs were to be extended to all eligible users and carers by April

²⁰ PBs cannot be spent on residential care.

2013, preferably as a DP (Routledge & Lewis 2011; ADASS 2012). PBs maintained most of the features of the piloted IBs, as depicted in Table 3.2, most notably regarding its use and deployment and the possibility for PBs to be spent on equipments or mainstream goods and services. Nonetheless, while IBs had sought, and to a great extent failed, to pool together a wider range of funding streams, PBs would only be funded from adult social care (Moran et al. 2011).

Table 3.2 – Use and deployment options for Personal Budgets

Deployment of PB	Agency	Management/use
LA-managed PB	User chooses how the care needs are met and by which home care agency (among those contracted by the LA)	The LA commissions the care services on behalf of the user with a home care agency and the LA manages payments to the agency.
Direct Payments (1)	User chooses how the care needs are met and by which provider (meant in a broad sense as it may include PAs)	The user purchases care directly from the home care agency.
		The user directly employs a PA and is responsible for payment of wages, taxes and insurance (2).
Provider-managed PB (Individual Service Funds – ISF)	User chooses how the care needs are met and by which home care agency	The PB is held by one home care agency under LA contract, akin to a current account of services, from which the user can draw to receive care. The day-to-day arrangements are agreed between the user and the agency.

Source: Adapted from ADASS (2010).

Notes: (1) The DP can be held by what is considered to be a suitable person (e.g. a relative) when the user lacks capacity. The LA may be appointed by the user to act as the suitable person, but this is different from LA-managed PBs.

(2) The payment of wages, taxes and insurance – the actual management of the money – can be delegated by the user to a support agency.

One option was to take the PB as a benefit managed by the LA, which would commission services on behalf of the user with the user's preference taken into account however. A second option was to take the PB as a Direct Payment of cash, in which case the user would take responsibility for managing the benefit and for purchasing care services from home care agencies, employing a PA or a combination of both. When using the DP option to employ PAs, users would be responsible for the related social contributions and tax payments, as well as insurance (e.g. health, sickness and public liability) and fulfilment of general employment regulations (National Audit Office 2011). Finally, the PB could also be held and managed by a home care agency chosen by the user, with the latter maintaining responsibility over how and when the money was to be spent. Users were free to combine any of these options, so that, for

example, a user could use part of the PB to receive care services from a home care agency commissioned by the LA – LA-managed PB – and take the rest of the benefit as a DP to employ a PA.

In terms of agency and the dimensions of choice allowed, Table 3.3 provides an overview of the evolution of different choice mechanisms in England, from the earlier institutional consumerism reforms (*quasi-markets*), to DPs, IBs and the benefit that eventually was established in the wake of the IBs experiment: PBs.

Table 3.3 – Different choice mechanisms and dimensions of choice for home care

Choice mechanism	Agency	From whom	What	How	When
Institutional consumerism	Care managers	In theory, choice permitted over formal provider organisation (i.e. home care agency), but exercised by care managers	Needs, and how best to meet them, are assessed by care manager	Very limited	Very limited
Direct Payment	Users	Possibility to choose carer. This includes relatives except close co-residing ones.	Needs assessed by care manager, user decides how to meet them	Possibility to determine how if hiring a PA or a home care agency	Possibility to determine when if hiring a PA or a home care agency
Individual Budget/Personal Budget	Users	Possibility to choose carer if hiring PA and possibility to choose formal provider organisation. This includes relatives, although co-resident relatives are only allowed in exceptional circumstances	Assessment by user and care manager on the outcomes of care and determination of what contributes to meet those outcomes	Possibility to determine when if hiring a PA or a home care agency (also when PB is managed by 3 rd party)	Possibility to determine when if hiring a PA or a home care agency (also when PB is managed by 3 rd party)

Source: Author's compilation.

As PBs were set to grow in importance, three issues became more prominent in user choice policy in England: whether outcomes under PBs would improve for older people; whether changes of the assessment and use of benefits would lead to the desired increase of take-up of PBs as cash, i.e. as DPs; and to what extent LA-managed PBs would fundamentally depart from institutional consumerism. What follows is a summary of the evidence on each of these issues, building on both the evaluation of IBs and more recent research.

On the subject of improved outcomes, evidence was somewhat mixed. On the one hand, there were consistent reports of better responsiveness achieved with PBs taken up as a DP (Newbronner et al. 2011; Hatton & Waters 2011; ADASS 2011; Sheikh et al. 2012). Older people voiced how PBs allowed them to better meet idiosyncratic and sometimes shifting needs, and arrange care around their daily routines and family life, i.e. they had control over when and what care was provided (Newbronner et al. 2011; Sheikh et al. 2012). The possibility to have control over the person who provided care – in the case of those hiring a PA – was also credited to have increased satisfaction with care received (Ipsos MORIS 2011). Increased control, however, was not limited to those hiring PAs, for PBs had also helped users feel more empowered in their dealings with formal provider organisations, and this had contributed to their overall enhanced feeling of being treated with dignity and respect, a fact acknowledged by home care agencies themselves (Sheikh et al. 2012). Those who had previously received LA-commissioned care prior to the introduction of PBs reported improvements on how care was provided under PBs as well as an enhanced sense of control, even though it was unclear whether that was due to take up of PBs as DPs²¹ (Ipsos MORIS 2011).

On the other hand, however, the individual amounts of PBs provided to older people remained low²² (Glendinning et al. 2008; Moran et al. 2013; Jones et al. 2012). This severely limited the affordability of anything other than personal care and thus hampered older users from benefiting from the added flexibility and control that DPs could allow (Netten et al. 2012). Unlike younger disabled people, who welcomed and took full use of the possibility to spend the DPs on a wider range of services, older people also appeared to be more cautious with the use of DPs. The care plans of older people were thus mostly built around personal care and support with domestic tasks, rather than on activities such as leisure or socialising activities (Glendinning et al. 2008). The use of DPs to access mainstream activities was further hampered by professionals' concerns regarding risk (Stevens et al. 2011; Moran et al. 2013). This had to do not only with using DPs for ends that tax-payers would deem defensible, but most importantly with professionals' concerns about the health consequences of some of the choices made by DP users.

²¹ The sample included people receiving PBs as DPs and as LA-managed and 3rd party-managed PBs; it is not clear to which of these groups those reporting improvements belonged to.

²² In the case of the IBs, certain streams of funding, such as the ILF, were not accessible to older people and thus could not be included in IBs for this user group.

On the issue of take-up of DPs, PBs had not substantially changed the picture and DPs remained confined to a minority of older users. The figures on Table 3.4 show that the number of users of PBs in general, and of DPs or DPs taken together with managed PBs in particular, has grown since 2009/10. One should not forget that specific targets were imposed for the expansion of PBs: 30% of all home care users by April 2011, expanding to 70% by April 2013. It is also clear, however, that take-up of PBs as DPs remained lower for older people than for other groups of users. A survey on PBs delivered in English LAs conducted by the Association of Directors of Adult Social Services (2011), reported that although the number of PBs was increasing, most of this increase was due to the managed PBs. Overall DP numbers had somewhat plateaued.

Table 3.4 – Distribution of PBs by type of deployment and user group

	Type of deployment of PB	Physical impairments (%)	Mental health (%)	Learning disability (%)	Frail older people (%)
2009 /10	DPs	4,235 (34.2%)	1,065 (38.4%)	2,235 (25.1%)	6,715 (11.4%)
	Managed PBs (LA and provider-managed)	6,460 (52.2%)	1,425 (51.4%)	4870 (54.7%)	49,090 (83.1%)
	Mix of DPs and Managed PBs	1,695 (13.7%)	280 (10.1%)	1,795 (20.2%)	3,300 (5.6%)
	Total	12,385 (100%)	2,770 (100%)	8,900 (100%)	59,105 (100%)
2010 /11	DPs	12,555 (28.2%)	2,615 (29.0%)	7,050 (22.4%)	15,465 (6.8%)
	Managed PBs (LA and provider-managed)	26,770 (60.2%)	5,645 (62.7%)	19,790 (63.0%)	201,855 (88.6%)
	DPs and Managed PBs	5,140 (11.6%)	745 (8.3%)	4,580 (14.6%)	10,440 (4.6%)
	Total	44,465 (100%)	9,005 (100%)	31,420 (100%)	277,750 (100%)
2011 /12	DPs	20,070 (29.1%)	4,490 (25.8%)	11,470 (21.1%)	26,825 (7.6%)
	Managed PBs (LA and provider-managed)	40,045 (58.2%)	11,420 (65.6%)	35,190 (64.7%)	307,055 (87.5%)
	DPs and Managed PBs	8,750 (12.7%)	1,490 (8.6%)	7,745 (14.2%)	17,040 (4.9%)
	Total	68,860 (100%)	17,405 (100%)	54,405 (100%)	350,915 (100%)
2012 /13	DPs	24,835 (30.6%)	6,570 (25.1%)	15,135 (20.0%)	30,080 (7.4%)
	Managed PBs (LA and provider-managed)	45,690 (56.2%)	17,480 (66.7%)	49,050 (64.8%)	353,630 (87.2%)
	DPs and Managed PBs	10,715 (13.2%)	2,145 (8.2%)	11,560 (15.3%)	21,780 (5.4%)
	Total	81,240 (100%)	26,190 (100%)	75,745 (100%)	405,495 (100%)
2012 /13	DPs	27,145 (31.1%)	7,490 (24.1%)	17,830 (20.8%)	32,710 (7.7%)
	Managed PBs (LA and provider-managed)	48,910 (56.0%)	21,075 (67.8%)	54,495 (63.7%)	368,175 (86.5%)
	DPs and Managed PBs	11,285 (12.9%)	2,535 (8.1%)	13,255 (15.5%)	24,545 (5.8%)
	Total	87,340 (100%)	31,105 (100%)	85,575 (100%)	425,445 (100%)

Source: NHS (2014).

Notes: Physical impairments, mental health and learning disability all refer to those aged 18-64. Frail older people refer to users aged 65 and older. Substance misuse and other vulnerable people were not included.

The figures testify to the fact that some issues with take-up of DPs lingered. Across studies and surveys, older users consistently expressed doubts and concerns about lawfully spending DPs, and in fact some were not even aware they could take PBs as a DP of cash to employ a PA (Hatton & Waters 2011; Sheikh et al. 2012). In a study on the experiences of older users and those with mental health problems conducted by Newbronner et al. (2011), older users were wary of using their PB in an unlawful way or to overspend, even if there was little evidence of this actually happening. It did not help that users were not always aware of the exact amount of their PB or DP, or how it had been calculated in the first place (Needham 2013). Difficulties and uncertainties in managing the DP could therefore result in increased anxiety and lower psychological wellbeing among older users as the evaluation of the IB experiment had shown (Glendinning et al. 2008; Netten et al. 2012).

These practices should be understood in the context of budgetary constraints faced by LAs at the time of the expansion of PBs (National Audit Office 2011). LAs slowly but steadily began to restrict eligibility to *Substantial* and *Critical* levels of needs only, and sometimes to the latter only, meaning that only very frail older people or those with dementia were likely to be among the users of PBs (Care Quality Commission 2011)²³. The over-safeguarding attitudes of care managers regarding management of risk when users took-up DPs or demanded more creative care solutions were likely to be more evident in the case of frailer older users.

Furthermore, as reported by both users and care managers in the evaluation of IBs, lower DPs might simply be perceived as not being worth the extra responsibility and management burden to get the same care (i.e. personal care) that LA-managed care would deliver (Moran et al. 2013).

Finally, the above reviewed studies and surveys confirmed the fundamental issue with DPs and older people, as had already been pointed out by Glendinning (2008) in the wake of the IB experiment. This was also illustrated in the theoretical literature on the limits of the consumerism discourse concerning choice reviewed in section 2.3.3. The first contact of older people with the benefit is liable to take place in a moment of crisis or bereavement, following a sudden deterioration of health or loss of a spouse or carer. Decisions over deployment

²³ In 2003, the eligibility criteria for access to social care was reorganised around four levels of need – low, medium, substantial and critical – partially in an attempt to provide some homogeneity in the eligibility rules across LAs (Lewis & West 2014).

options of PBs are often made at a moment when older people have to cope with changing circumstances in their lives and uncertainty about future needs.

Despite the prevalence of managed PBs amongst older people, there is a dearth of empirical studies on how users experience LA-managed PBs and how far they differ from institutional consumerism. What evidence exists from the viewpoint of users shows less positive outcomes (than those of DPs), and more standardised services being provided through managed PBs. These are accompanied by reduced awareness on the part of users on how the PB is managed and on choices available to them (National Audit Office 2011; Hatton & Waters 2011). Recent research shows LAs making efforts to adapt commissioning to deliver more choice alongside efforts to diversify supply of available services through market development initiatives (Wilberforce et al. 2012; Baxter et al. 2013). A study on LA-managed PBs by Baxter, Rabiee and Glendinning (2013), in particular, showed LAs still to be very much in control of how care was provided through LA-managed PBs. Some LAs have set up Individual Service Funds (ISF) which corresponded to PBs held by a 3rd party, in this case home care agencies, but where users have greater freedom to define how and when care is provided directly with the home care agency. Subsequent changes can be negotiated without having to obtain prior LA approval.

Outcomes of PBs and take-up of PBs as either DPs or managed PBs therefore remain interconnected issues. DPs still seem associated with more creative ways to arrange care and these in turn are associated with better outcomes. In their analysis of the POET survey results, Hatton and Waters (2011) caution that the less favourable outcomes experienced by older users may owe less to old-age per se than to the more conservative use of PBs.

Although IBs had initially sought to tackle some of the barriers hindering the take-up of DPs and expand the dimensions of choice allowed to users, it is not clear that its successor, the PBs, have resolved those issues. Importantly, eligibility and available resources continued to grow tighter. It is contentious whether PBs provide enough purchasing power for users to get more than the bare minimum. By providing differentiated deployment options, PBs were supposed to create an enabling environment for *choice for all seasons*, i.e. tailored to the wishes of different users: DPs for users turned consumers or willing to become employers of care; or “managed PBs” for users craving for control but welcoming a helping hand from LAs or home care agencies in supporting their choices. It is not clear that the former is available to all or that the latter provides sufficient control to users.

3.3 CRITICAL ASSESSMENT OF CHOICE IN ENGLAND

The pathway to user choice in long-term care in England has been characterised by a strong consumerism discourse (cf. Le Grand 2007), which not only reflected NPM theories aiming to improve efficiency of long-term care services, but also fitted with the agenda of the disability rights movement that aimed to have more control and independence. In reality, however, users of care have only recently been empowered to make relevant choices on their own. The initial reforms of the 1990s mostly focused on creating a mixed economy of care provision, to bring about improved efficiency and outcomes and particularly to curb public expenditure on expensive residential care, rather than on actually widening the dimensions and capabilities of choice for users. Older users of care had to wait until 2000, when DPs were expanded to older people, to gain agency over care and for choice to expand and include several of Le Grand's (2007) dimensions of choice, most notably choice over *from whom* to receive care. One can say that it was only with the introduction of the PBs that user choice mechanisms in place finally matched the consumerism and personalisation rhetoric that had been particularly dominant since the early 2000s in the reforms introduced in long-term care in England (Needham 2011).

Currently, users that opt for DPs are arguably those whose experience would come closer to the view of sovereign consumers of care. For example, they have in principle agency over a wider range of choice dimensions than those on LA-managed PBs. Despite the opportunities for older people to have control over how they spend their PBs, the fact remains that taking PBs as a DP remains the choice of only a minority of older people. This is in stark contrast with the take-up of DPs by other groups of users, namely disabled people of working age, as well as older people in other countries that offer the option of direct payments of cash, such as in the Netherlands and Germany. If one is to believe the consumerism rhetoric, it would seem as if the majority of older users of care would thus be forfeiting the benefits of choice.

The reasons for the lower take-up presented by the research reviewed in this chapter are multiple if somewhat still speculative. In the English context, user choice has been introduced against a backdrop of budgetary cuts to public spending on long-term care, which has often been translated into lower individual PB amounts. Older people in particular have continued to have lower PBs. As greater satisfaction with DPs is associated with the ability to creatively use the amounts left once basic needs are met, one line of reasoning argues that older people might just not bother to take DPs. The benefits associated with the reduced amounts might be deemed small in comparison with the stress and anxiety of managing DPs. While there is no

denying the influence of budgetary cuts on the development of choice in England as a whole, take-up of DPs by other groups does not seem to be as affected by this.

Another stream of thought blames care managers' over-protective attitudes and actions towards older people's vulnerability and ability to choose, which in turn would only reinforce passive attitudes of these same users. While the importance of care managers in supporting user choice is well established, research into the reported views and attitudes of care managers towards PBs and DPs have found these to range from caution, to support, and engagement with user choice. In other words, it seems that care managers can hardly be portrayed as a homogeneous group of conservative blockers of user choice.

The flipside of the argument of the role of over-zealous care managers is that it is actually older people that are much more conservative and cautious in their use of benefits. According to this alternative narrative, either because of age or cohort effects, choice would simply have less intrinsic value for older people. The research reviewed here on older users exercising choice, namely the one carried out in the context of the evaluation of IBs, showed, however, that older users also valued the added sense of control and the greater continuity of care associated with the possibility to use DPs to hire their own carers (Stevens et al. 2011; Moran et al. 2013). This stands in contrast with the view of older people as helpless or passive recipients of care.

Without subscribing to the view of users as passive recipients of care, or as being unable to derive satisfaction from choice, other researchers, such as Glendinning (2008) and Baxter and Glendinning (2013), point to the impact that circumstances around choice and the profile of older users of PBs might have on the decision to take PBs as DPs. Older people tend to become eligible, or come into contact with social care and DPs in times of crisis, for example, following sudden deterioration of health, discharge from hospital, or when other care arrangements have broken down. Under these circumstances, making choices can be felt as a negative emotional experience and this can impair decision-making and turn older people away from making choices or acting as informed consumers (Baxter & Glendinning 2013). Citing insights from psychological studies, Beresford and Sloper (2008) point out that decision-making under stress may generate fear and anticipated regret (see Chapter 2). In the absence of emotionally supported decision-making, this could also explain why older people might prefer to avoid making choices or take a more conservative view as to the use of DPs.

Most likely the low take-up of DPs cannot be explained by any of the above factors alone, but rather by their interaction. For example, tighter long-term care budgets may have restricted

eligibility to the frailest amongst older people, many of them with dementia. They are more likely to be more dependent on the support from care managers to exert choice, while at the same time more prone to be viewed by those same care managers as less able to exert choice, or likely to make the wrong choices.

The narrative of the implementation of user choice policies in England made it clear that disabled people of working age and among them physically disabled people or people with learning disabilities played a pivotal role in the fight for more control over the use of care benefits with the aim to achieve independent living and personalization of care services. The demands of a particularly vocal group of disabled people, those with physical impairments, were decisive in shaping DPs, namely, by pushing for the possibility to employ their own paid carers. Similarly, advocates of adults with learning disabilities were instrumental in the development and expansion of the PBs to other user groups through the experience of *In Control*. Older people and their own personal expectations of what independent living means (cf. Rabiee 2013), were more often than not simply hidden/obscured behind the leading voices of the disability rights movement. It is pertinent to question how much older people saw their views reflected in the policy changes introduced and to what extent DPs actually became a sort of *choice for all seasons*.

It is not entirely clear whether the experiences of older users of care with choice resemble those of disabled people of working age, or whether the consumerism discourse surrounding user choice fits all older users of care. For example, many users with dementia may have limited sovereignty regarding their choices (Eika 2009; Glendinning 2008). In fact, the evidence summarised here suggests that older users of care might have different expectations and act somewhat differently to other user groups. Despite a sizeable body of research on the outcomes of choice for older people, there remains nonetheless a non-negligible gap in the empirical literature of how older users experience choice in the context of long-term care and what determines their decisions regarding how to use DPs.

Two exceptions are Baxter and Glendinning's (2013) research on the role of emotions in the decision making process and Rabiee's (2013) study on choices made by disabled and older people. The former study confirms that choice-making in long-term care is a (mostly negative) emotionally-laden process in which people often postpone decisions or act on the basis of instinct rather than the strict weighing of options. The processes of making choices described in the latter study include decisions that are made not only with the user's own interest in mind – for example, when users make choices that enable them to stay near relatives so that they can still provide grand-parenting. These also include trade-offs, most

notably when related to the employment of relatives. Both studies however, include but do not focus specifically on older people.

3.4 CONCLUSIONS

Chapter 2 had previously highlighted, from a theoretical standpoint, the potential importance of relationships in the context of care and therefore the possible influence of relationships on the decisions of users in their capacity as consumers. While reviewing the process and outcomes of introducing competition and choice in long-term care in England, two gaps emerged concerning the issue of the relational aspects of care and decisions made by users. The first refers to the knowledge of how older users of DPs make their decisions regarding care. Users of DPs of working age have merited a relatively large body of research in the context of long-term care in England. By comparison, research on older users of long-term care has more often focused on those receiving LA-managed care or on the comparison between this group and those on DPs, but without focusing on the different choices made by the latter concerning the deployment of the DP. This gap is particularly striking given the relatively low take-up of DPs among older users and the fact that DP users, whatever their age, are arguably the ones that come closer to the concept of consumers of care that has so often been present in the English debates and policy documents concerning long-term care.

The second gap concerns the role played (or not) by the relational aspects of care in the decisions of users of long-term care, and in particular of DP users. And yet, this is a potentially salient issue to understand the choices of users, as exemplified by an example from outside England. Empirical research conducted in Germany showed that preference for cash benefits among older people was strongly linked to the possibility to hire relatives as paid carers. This reflected strongly embedded views about what was considered to be “good care”, which assumed that family carers who were acquainted with the user would be more responsive to the individual preferences of older people (cf. Eichler & Pfau-Effinger 2009 for the German case). This example relates to the experience good nature of care highlighted in the literature review of Chapter 2, both in terms of the identity of the carer, rooted in the feminist literature; and in terms of how care is provided, which relates to Baldock’s (1997) concept of the user as co-producer of care. These themes, however, have been relatively overlooked in the research on DPs and home care in England with only two recent notable exceptions. Walsh and Shutes (2013) stress the importance attached by DP users to the emotional profile of their carers. This was deemed more important in the decision to hire them as opposed to more formal caring skills. Lewis and West (2014) highlight the still relatively unregulated nature of home care provision in England and the gaps in assessing

quality. For example, as yet, there is no compulsory national registry for PAs in place. Lewis and West's research, however, is not based on empirical evidence about the importance of relationships.

Given the experience good nature of care, as well as the asymmetries of information present in assessing quality in long-term care as discussed in Chapter 2, Lewis and West's findings add greater salience to the need to understand how older people using DPs make their choices and experience care in an environment of great uncertainty and lack of information about quality or the identity and suitability of their carers. This also includes the potential role played by relationships in these same decisions and experiences with care. The present thesis will therefore aim to contribute to bridging these gaps of knowledge. For this purpose, the next chapters will respectively narrow down the research scope to a tractable research question and hypotheses (Chapter 4) and suggest and describe in detail a suitable methodology to gather and analyse information on this topic (Chapter 5).

Chapter 4 : RESEARCH QUESTION AND HYPOTHESES FOR INVESTIGATION

The introduction of user choice in long-term care, coupled with competition between care providers, was intended to improve the satisfaction users derive from the care they receive. Users acting as rational consumers would purchase care from competing providers and thus be able to receive the care that best suited their needs, at the lowest possible price. However, the literature reviewed in Chapter 2 questioned the applicability of the concept of the rational consumer to older users of long-term care. Furthermore, given the risks of market failures and issues around equity of access and affordability of care for those who most need it, the state has arguably had greater scope for intervening in long-term care than in many other markets. The literature, reviewed in Chapter 2, also highlighted that long-term care may be *different* from other commodities traded in markets. Care comprises not only physical and potentially intimate tasks, but also the establishment of a deeper emotional bond – caring as a sentiment of concern (cf. Jochimsen 2003; Himmelweit 2007). If this premise holds, relational aspects of caring would be essential dimensions of quality and should therefore be central to the user's satisfaction and choices. The impact of relationships on choices and satisfaction of users has nonetheless been relatively overlooked in the discussion and empirical research around the introduction of user choice in long-term care.

One characteristic of relationships is that they are difficult to gauge *ex-ante*, i.e. before care has actually been delivered and experienced. If relationships are important in caring, this would make long-term care an example of what in economic terms is called an “experience good”. This characteristic alone has implications in terms of potential for issues of imperfect information to occur in long-term care. In order to deal with the uncertainty surrounding the experience good nature of care, users could try out different providers, be it paid carers or home care agencies, in search of the best match. Users, however, may be reluctant or unable to try out different paid carers or home care agencies as it may be time-consuming, exhausting and emotionally difficult to exit a relationship with one carer and search for a new one. In other terms, economists would say they face high “switching costs”. Taken together, these two characteristics mean that older users may face substantial risks of being trapped with a provider who delivers care unsuited to their preferences. This suggests the possibility that being able to decide upon the identity of the carer, or to hire one they already know, may thus be an important factor affecting users' satisfaction under different choice mechanisms.

The experience good nature of care and the impact of relationships in care may nonetheless go beyond the choice of *whom* to receive care *from*. The literature review in Chapter 2 highlighted another important concept pertaining to long-term care: namely Baldock's (1997) concept of the user as a co-producer of care. This is a salient concept in long-term care since the process of caring depends at the very least on the passive collaboration of the user, and satisfaction with the relationship and/or care tasks provided is therefore influenced by his/her own set of values. For example, as a co-producer of care, the user contributes to the relationship and therefore to the quality of care. The experience good nature of care thus goes beyond the choice of who provides care, to also encompass the tasks provided by the carer and how they are provided. Satisfaction with care received is therefore unlikely to arise from receiving standardised services (Kremer 2006). Nonetheless, the two issues are intertwined. Being able to choose the identity of the carer could also enhance the user's control over other dimensions of choice, such as choice over *when* care is delivered, *what* the contents of the care package are and *how* it is delivered. This could enable users to define the care package that best suits their idiosyncratic needs and thus entail increased satisfaction. If salient, the relational aspects of care could thus impact choices and satisfaction regarding care not only through the identity of the carer, but also through differential opportunities to define the content of care tasks i.e. when and how these are provided.

To empirically investigate the relevance of the relational aspects of care to the decisions and satisfaction of users of long-term care, and in particular older users, this thesis selected England as a case study. The choice of England was prompted by the fact that this country spearheaded the introduction of competition and choice in long-term care in the early 1990s. This process and its outcomes were charted in Chapter 3, which details the evolution from institutional consumerism in the early 1990s to regulated cash benefits or vouchers, with the implementation of Direct Payments (DP) of cash in 1997 and Personal Budgets (PB) in the 2000s (see Chapter 3). The PBs currently in place allow users to take up the benefit as a Direct Payment of cash which can be used to hire a personal assistant (PA), including in some circumstances an acquaintance or relative, or purchase services from home care agencies. PB users can also choose to hand over the management of the benefit to local authorities, service providers or another third party, whilst still - in principle - having a say over the care received. Users who take their PBs as DPs therefore come closer to resembling consumers of care.

A number of empirical studies were also surveyed in Chapter 3, particularly those with a focus on the experience of users of DPs (e.g. Arksey & Baxter 2012; Rabiee 2013; Baxter &

Glendinning 2013). These studies, however, mostly compare the outcomes of users who chose to take the DP as opposed to those who had conventional local authority-managed care services (institutional consumerism). Another focus of the research has been the use of DPs to employ a personal assistant. These latter studies tend to focus on the issue of being in control or deriving satisfaction from the possibility of exerting choice. The focus has also been on the trade-offs in terms of stress and tension that can be derived from having to make decisions²⁴ and manage DPs, i.e. the intrinsic value of choice.

Relatively less attention has been devoted to the choice processes and outcomes of those who do not rely on the local authority (LA) to manage their care and have chosen to take DPs, i.e. those that come closer to being consumers of care²⁵. Indeed less focus has been placed on the motivations, process and experience of older people using a DP to hire carers or purchase care services, or the factors underlying one or the other choice (Manthorpe et al. 2011; Arksey & Baxter 2012). Similarly, the role played by the relational and co-production aspects of care in the choices and experience of users with care as outlined above also remains under-researched. The present research aims to address these gaps in knowledge.

As mentioned above and as detailed in Chapter 3, users of DPs have different options to deploy their benefit. These options make it possible to investigate how the relational dimensions of caring shape choices and experiences of care. For example, some of these options directly relate to the relational aspects of care that this thesis aims to address, namely the possibility to choose a particular carer by hiring a PA and the possibility to hire an acquaintance or relative as the PA. This feature of the DP will be convenient to narrow down the above-stated general aim – to investigate the impact of the relational and co-production aspects of care on the choices of older people and their experience with care – into a more tractable and confined research question and set of hypotheses. By exploring different choices made – for example, hiring a PA or purchasing care from a home care agency – this thesis will analyse how these decisions may have, for example, reduced the uncertainty associated with the relational aspects of long-term care; allowed for the establishment or the continuation of a rapport with the paid carer; and made care options better suited to the needs and preferences of users.

²⁴ A related issue is the reluctance to take responsibility for managing the employment and financial accounting involved in employing a personal carer.

²⁵ Apart from those who self-fund their own care.

4.1 RESEARCH QUESTION

As mentioned above, the relational aspects of care could impact on choices and satisfaction of users via the identity of the carer and the definition of care tasks. Focusing on older users of PBs in England who have taken the benefit as cash, i.e. as a DP, and building on the different possibilities users have to deploy DPs, the **main research question** of this thesis is:

How and why are users' experiences of care affected by choosing to hire a personal carer rather than to acquire services from a formal provider?

Drawing on the theoretical insights reviewed in Chapter 2, it is hypothesised that hiring a PA or paying informal carers could entail higher user satisfaction than contracting a formal service provider, in two possible ways:

- By allowing the user to choose from whom to receive care, which matters to the user given the relational nature of long-term care – hypothesis 1, as described in detail below.
- By increasing the leeway that users have in defining what, when and how care is provided – hypothesis 2, as described in detail below.

Hypothesis 1. The possibility to choose and employ one's own carer would entail higher user satisfaction because users value the relational aspects of care and the possibility to choose *from whom* to receive care.

Regulated cash benefits such as DPs give users the ability to choose from a more diverse range of care providers, as DPs may remove barriers to entry faced by providers. One example is associated with the expertise or organisational capacity needed to successfully bid for contracts tendered by public authorities. This allows for the specialisation of smaller providers in niche markets of care (Baxter et al. 2011) or for individual PAs to enter the market. This in itself could entail increased user satisfaction, by enhancing competition and providing a better match between users' preferences and the care provided as users with DPs are able to act as empowered purchasers.

The case made here, however, is that what is particularly valued by users is the ability to choose the identity of their carer and establish, maintain or develop a rapport with the carer (the latter case if the carer is already known to the user). This stems from the relational nature inherent to caring highlighted in Chapter 2. According to this hypothesis, the relational nature of caring is valued by those in need of care. The different modes of deployment of PBs

provide users with potentially different degrees of command over the identity of their carer, for example, by hiring as a PA someone they may or not have previously met. The relational nature of care could thus also impact the choice of deployment. Hiring someone the user knows, or who is already caring for the user, may be a way to deal with some of the uncertainty associated with both the experience good nature of care and the unwillingness or inability of users to change provider frequently. This is particularly relevant in the context of imperfect information (see Chapter 2). In this case, the user is already knowledgeable about at least part of the relational component of care²⁶. Even if the user is not already acquainted with the carer, having the possibility to choose the latter's identity could still allow the user to develop and invest in the relational aspects of care, as well as gather further information beforehand through the recruitment and hiring process (e.g. by conducting an interview). As relationships may change over time, and may indeed require time to develop, it is also salient for hypothesis 1 to analyse how the relationship nature of care evolves over time.

Hypothesis 2. The possibility of hiring a PA or paying an informal carer increases user satisfaction by allowing users to better shape the care they get to their needs and preferences.

The experience good nature of care is not confined to its relational component, but applies also to the tasks performed by the carer. A greater command over the identity of the carer may allow users to better shape the tasks or the timing of care they receive or both, i.e. the *when, how and what* (Le Grand 2007). This means that users may be more able to shape the care they receive to their preferences and needs, while even accommodating for changes in these same needs and thus derive greater satisfaction from this arrangement. This could take place because users have greater bargaining power with a PA whom they directly employ and manage themselves, or because the latter may be faced with less stringent company regulations regarding the delivery of care. Users may also derive more satisfaction from the simple fact of being able to choose, or having command over choice – i.e. the intrinsic value of choice. It is not, however, satisfaction attached to the mere possibility of choosing that this study aims to analyse here. It is rather the satisfaction derived from receiving care that best suits the users' needs and preferences.

²⁶ Furthermore, the user could also be knowledgeable about the ability of the carer to provide care according to the user's needs and preferences, although this would not pertain directly to the relational nature of care.

Building on the gaps identified in Chapters 2 and 3, this Chapter formulated the research question and hypotheses that will be empirically analysed in this thesis. The next chapter will detail and justify the methods employed to investigate this research question.

Chapter 5 : STUDY DESIGN AND METHODS

The previous chapter presented the research question that this thesis aims to address: *How and why are users' experiences of care affected by choosing to hire a personal carer rather than to acquire services from a formal provider?* To address this research question empirically, England was chosen as a case study, and in particular older users of PBs that have taken their benefit as a DP. Drawing on the theories reviewed in Chapter 2, in particular the relational aspects of care theorised in the sociology literature, as well as on the different possibilities to deploy DPs available to users, two hypotheses were formulated.

The first hypothesis is that the possibility to choose the identity of the paid carer (i.e. *from whom* to receive care²⁷) is an important driver of users' choices and satisfaction because users value the possibility to build on or establish a relationship with the paid carer. Under the second hypothesis, it is conjectured that the ability to choose one's carer may also increase users' leeway in determining how, when and what care they receive and this would more closely shape care to their needs and preferences.

Having defined the research question and accompanying hypotheses, questions remain as to what data to collect, how best to collect these data and which methods are best suited to analyse these data. This chapter aims to provide a detailed description and discussion of the study design and methods employed to gather and analyse data to investigate the above-stated research question and hypotheses. The first section of this chapter begins by providing the methodological justification for the methods subsequently employed to gather and analyse data. It goes on to include an exhaustive account of the study design and methods employed to gather data, including sampling strategies. The latter includes the aims and foreseen steps at each stage of the fieldwork and the description of how the fieldwork actually took place, drawing implications for the robustness of findings. The second section critically depicts the methods employed to analyse the data collected in the fieldwork. Finally, section three debates issues around ethics and research governance linked to the collection and analysis of data.

²⁷ The expression *from whom* to receive care, directly taken from Table 2.1, will be used interchangeably with the equivalent expression *who provides care* throughout this study.

5.1 STUDY DESIGN, DATA AND METHODS FOR DATA COLLECTION

5.1.1 METHODOLOGICAL JUSTIFICATION FOR THE CHOICE OF STUDY DESIGN

Qualitative research methods have long been linked to research that seeks to understand *why* a certain social phenomenon takes place and what influences it (cf. Ritchie & Lewis 2003; Yin 2009). According to Ritchie (2003, p.28), one of the main advantages of qualitative research methods is that they allow for questions to be studied with great detail and thus provide “a unique tool for studying what lies behind, or underpins, a decision, attitude, behaviour or other phenomenon”. The research question and hypotheses detailed above clearly pertain to the understanding of the underlying process that underpins choice in long-term care.

Still according to Ritchie (2003, p.32), qualitative research methods are furthermore deemed most appropriate when the research question “is concerned with understanding context or process”, or when the subject of research pertains to deeply rooted values (e.g. family values). It could also involve personal representations and views over one’s self (e.g. convictions about personal autonomy). The literature review (see Chapter 2) made clear that although choice is firmly embedded in economic theory, its application to long-term care raises issues related to the particularities of the concept of caring. Not least of all, caring is in itself a value-laden concept, shaped by social norms and moral motivations, in line with Granovetter’s (1985) previously stated concept of socially embedded choice (see section 2.3.3). This makes qualitative research methods relevant for the study of the impact of contextual factors (e.g. social values) on choices made by older people.

Finally, it was also clear that choice in the context of long-term care often takes place in a context of crisis (Glendinning 2008; Baxter & Glendinning 2013). When gathering information from individuals, qualitative methods allow the researcher to probe and adapt the questions to the circumstances of the individual. They are thus particularly suited to gather information regarding sensitive topics such as choice of care following the deterioration of one’s own health, previously dissatisfied experience with a carer, or death of a close relative who was also a carer. Probing is also particularly suitable to recollect past events, particularly when using semi-structured interviews as is the case in this study. Furthermore, probing in the context of semi-structured interviews is a fairly accurate way to recollect past events; it also makes it possible to explore issues not anticipated by theory or covered in previous empirical research as they emerge (Lewis 2003).

Qualitative research methods are also often associated with inductive reasoning where data gathered is used to generate theory *ex-post* and hypotheses stem from the data. In fact, the use of inductive reasoning in qualitative methods is often contrasted with deductive reasoning, where data are used to test theories established *ex-ante*, often associated with quantitative methods (Snape & Spencer 2003). The above stated hypotheses and the deductive reasoning that to some extent underpin the research question above (e.g. by using three comparator groups) could thus seem at odds with the *modus operandi* of qualitative methods employed in this study. The use of qualitative methods in a deductive frame of reasoning is, however, neither new nor contradictory. Among others, Patton (2002) argues that both inductive and deductive reasoning can be used by qualitative researchers at different stages in their studies. Deductive reasoning is also routinely employed in case study analysis – a specific qualitative research method – where a number of hypotheses are described beforehand. Matching or contradictory cases are then used to validate or further fine-tune theory (Yin 2009). The use of hypotheses can also be important in defining *ex-ante* typologies (see next section on study design) that help to gain insights into the topics researched (Bechhofer & Paterson 2000; as cited by Lewis 2003) and also in directing the initial stages of the analysis. Regarding the latter, hypotheses can be used to guide the construction of the initial framework or thematic index that is subsequently populated with codes emerging from the narratives of users (Miles & Huberman 1994), which will be described in detail in a latter section in this chapter (see section 5.2.1).

A number of authors propose the use of both inductive and deductive reasoning at the stage of data analysis. They defend the advantages of starting the coding process (e.g. of interview transcripts) with a set of themes derived from theory or previous empirical studies and then incorporate codes that stem from the data itself (Fereday & Muir-Cochrane 2006; Hsieh & Shannon 2005). Furthermore, Bechhofer and Paterson (2000; cited in Lewis 2003, p.50) defend the idea that comparisons and control – which are intrinsic to deductive reasoning – are key components of sound research regardless of the methods used. In her discussion of designing issues, Lewis (2003, p.50) recognises the usefulness of drawing comparisons in qualitative research as a way of “understanding rather than measuring differences”, albeit at the cost of demanding a more careful approach to the collection of data to allow for meaningful comparisons between groups in the sample. In discussing their proposed Framework Analysis for qualitative research, Ritchie, Spencer and O’Connor (2003, p.222) employ deductive reasoning to first establish a structure of themes that is conceptually clear. They then use an inductive theory-building analysis, by including codes and expanding themes that stem from the transcribed interviews (see section 5.2.1 below). It seems

therefore that a credible and wide enough body of literature exists to support the use of a combination of deductive and inductive reasoning in qualitative research methods such as the one employed in this study. Furthermore, it is worth restating that this study's main goal is not to test the hypotheses defined above – i.e. they are not the end of this study – but rather to use them as tools or means to explore the main research question.

5.1.2 STUDY DESIGN

The study focuses on old-age users receiving care in their own homes, and specifically on those that chose to receive their PBs as cash (i.e. as a DP) to hire a PA or purchase care services from home care agencies themselves. The decision to concentrate on users of DPs is justified by the fact that these are the ones that come closest to the definition of users as consumers of care. Indeed they are allowed choice over a wider set of dimensions of care (see section 3.2.2). Of particular interest to the research question of this thesis is the fact that DP users have greater control over choice of *from whom* and *when, how* and *what* care to receive compared with users of LA-managed care. For example, unlike the latter, DP users are able to directly employ carers as their PAs – which is of direct relevance to the research question under analysis in this thesis. They are also not limited to the home care agencies that are under contract with the LA and may find less administrative barriers to change agencies when compared with users on LA-managed care (see section 6.1). DP users therefore come closer to the notion of users as consumers of care. This thesis does not cover those in institutional care since many of the user choice mechanisms are confined to publicly funded home care, and some of the most important issues of interest make more sense in that context, most notably the choice of carer. Furthermore, older people arguably face more barriers to exit providers in institutional rather than home care, for example due to their health condition or to geographical constraints (e.g. preference to remain close to relatives).

In line with the previously stated arguments in favour of using comparisons set forth by Bechhofer and Peterson (2000) and Lewis (2003), this study has a comparative component. It focuses on three groups of older people receiving DPs in their own homes, but who differ in the choices they have made in regard to the use of the DPs. The aim is to get a better understanding of the role played by the relational and co-production aspects of care. As alluded to above, the three groups comprise older users of DPs that have chosen to hire someone they previously knew (e.g. relative, friend, neighbour, previous agency carer); older users of DPs that have chosen to hire as a PA someone previously unknown to them; and older users of DPs that have purchased services from a home care agency (i.e. a formal provider organization). Each group is detailed below:

- Users that hired a PA previously known to them – hereafter denominated as **“employer + relational” users** or **“relational”** for short. The agreement over how and when care is provided can be seen as taking place within a familiar relationship. This group gets their “employer” denomination from being able to hire and manage their own carers and thus possibly having greater leeway in also shaping the other aspects of care received (linked to hypothesis 2). The “relational” aspect refers to the fact that these users would have circumnavigated the uncertainty aspects of the experience good nature of care, or at least those related to the relational aspects, by hiring someone they previously knew and/or by possibly also having greater leeway to develop these same relational aspects of care (linked to hypothesis 1).
- Users that have used the DP to hire a previously unknown person as their PA – hereafter denominated as **“employer” users**. These users have become employers of their own carers, similarly to users of the first groups, and may have more leeway to determine what and how they receive care (hypothesis 2). Although the experience good aspect of care is still present, both in terms of the relationship and how and when care is provided; they have the power to interview their PA – thus gathering more *ex-ante* information about the relational aspect of care – to change PA, or to build on a relationship with their PA (hypothesis 1). The agreement over how, and when, care is provided takes place within an employer/employee relationship.
- Users that have used the DP to contract the services of a formal care provider – hereafter denominated **“purchaser” users**. These users have become consumers of care, having to deal with the experience good nature of care in selecting the provider and having arguably less leeway to choose the identity of the carer. As they purchase care from an agency, they may have less chance to get prior knowledge over the relational aspect of care (hypothesis 1) and, according to hypothesis 2, more limited possibilities to determine how and when care is delivered. Agreement over how and when care is delivered is done within a consumer/provider relationship.

The rationale for employing this comparative design is the following: these three groups could potentially have contrasting experiences in choosing, negotiating and experiencing care in relation to the experience good nature of care and the above-stated hypotheses. Each of these three groups bears a different relationship to the potential advantages of choice described by the two hypotheses. Group 1 potentially benefits from (A) both prior

acquaintance with the carer and ability to build on an existing rapport with the carer and (B) closer managerial control, as described by hypotheses 1 and 2 respectively. Group 2 potentially benefits from (B) but not (A). Group 3 is not able to benefit from either (A) or (B). Groups 2 and 3 therefore overlap in not having prior acquaintance with the carer at the initial moment when making their choices. It is nonetheless possible that they too develop relationships with the carer over time and that these relationships come to impact their experience of care. Another salient overlap exists between groups. Both group 1 and 2 have agency over the choice of their carers; while presumably those in group 3 are more limited in this. This is salient to the first hypothesis, which states that choice over who provides care is important to users.

The use of typologies, including those defined *ex-ante*, is often the employed mean in qualitative research to establish associations and clusters in qualitative data (Spencer et al. 2003). The above described three groups, or typology of older DP users, were therefore used to explore patterns and links that contribute to a better understanding of the relational and co-production nature of care. The purpose is not to generalise about choices made by each group, but to draw inferences and to compare the relative importance of the roles played by the relational and co-production aspects of care when making choices in long-term care. This is salient both in terms of differences and similarities between the three groups of users. The comparative analysis between the three groups of users also serves to highlight particular themes or topics that might not seem so relevant in the context of the whole sample, but that attain a particular importance for one group and thus allow for a deeper understanding of choices regarding one specific group or issue. The use of typologies also enables the exploration of barriers or opportunities to develop relationships and receive good quality care that might be particular to any group of users.

The experience good nature of care and the focus of this study on the user's experience with care received make it salient to consider not only the moment when decisions concerning care choices were made (e.g. hiring a PA or acquiring services from a formal provider). The development of a rapport with the carer – in case the carer was not a previous acquaintance – or the realisation of how the relationship with an acquaintance employed as a carer might have changed takes time to develop. The negotiation process of setting the care tasks, as well as how and when they should be provided, is also likely to be of an on-going nature, or at least to involve some adjustment particularly at the beginning of the care relationship. Finally, views on experiences with care received are likely to be more accurately expressed after some time has elapsed in the care relationship, and after interviewees have had time to

reflect on subsequent developments, whether positive or negative in the relationship. For example, if there is some degree of trial and error involved in choices and development of relationships, sufficient time needs to elapse for this to be accurately reflected on the narratives of users. It is therefore salient to investigate the impact of the experience good nature of care not only at the time of making the initial choice, but also in terms of how it evolved over time, thus following the example of other studies on the subject that analysed these temporal dynamics (Arksey & Baxter 2012; Rabiee 2013; Baxter & Glendinning 2013). It would thus be possible to assess how after some months into the caring relationship, users perceive the relational aspects of care, the possibility of shaping other dimensions of choice, and their satisfaction. This needs to be balanced with the potential for recall bias when reflecting on the original choices, and thinking at the time these initial choices were made.

The study is divided into three stages:

Stage 1 (LA context): Selection of the LA and review of its market context, namely by consulting existing information (e.g. booklets, websites) and previous studies (if available) and conducting interviews with three to four LA officials including frontline staff as well as senior managers of adult social services.

Stage 2 (old-age user interviews): Sampling of older DP users and interviews with the three groups of older users of DP described above.

Stage 3 (comparative data analysis): Qualitative data analysis of the transcripts of interviews.

The **first stage** involves selecting the LA and conducting a mostly descriptive study on the context of care in this selected LA (see section 5.1.3, below). This includes not only describing the assessment and referral process, but also the “market context”. The former is important to determine over what dimensions of choice users had agency (see Table 2.1 in Chapter 2), the role played by care managers, how users first came into contact with providers or care options, what rules applied to the use of DPs (e.g. to what extent DP users pay the same fees for care provided by home care agencies as LA-managed care) and what support mechanisms are in place. The latter is important to gain insights on how the users performed their search and why they eventually settled for the choice they made (e.g. lack of competition may reduce the number and variability of care options). This is particularly relevant in light of possible imperfect information, as discussed in Chapter 2. The market context pertains also to the concept of *choice set* (Klein & Millar 1995) referred to in Chapter 2, i.e. to the possibilities

from where to choose from. The information collected in this first stage is also important to understand potential opportunities or barriers to receive care and establish relationships, for example, regarding constraints imposed by home care agencies on their staff, or constraints on users' choices, for example, those resulting from lack of information when searching for PAs. Available public information is to be supplemented with more detailed information on the above themes to be collected from three to four local officials including frontline staff as well as senior managers responsible for adult social services or staff from support agencies – hereupon collectively denominated “care managers”. These interviews aim to collect descriptive information about existing care providers, the needs assessment process of people needing care, the definition of the care package and the referral process to providers of care.

The **second stage** of the study mostly comprises sampling older DP users and gathering information from them on their decision-making process when selecting care and how this was impacted by the experience good nature of care, particularly (but not exclusively) its relational dimension and subsequent relationship development (see sections 5.1.4 and 5.1.5, below). In this second stage, data is collected through in-depth semi-structured interviews with DP users – see below sub-section on methods and data collection – on a number of themes. In particular, some of these themes are enumerated as follows: how they value the relational aspects of care – choice over who – and how their relationship with the carer has evolved; how they value choice over other dimensions of care (e.g. what, how and when) and how they negotiated these other dimensions with their carers; and how they perceived their experience with care received and what has influenced this experience.

The **third stage** of the study comprises the analysis of the qualitative data for the whole sample of DP users by using the Framework Analysis (Ritchie & Lewis 2003). This third stage of qualitative data analysis also introduces the comparative analysis between the three types of users (see section 5.2, below). The use of the above described typology aims to supplement and deepen the understanding of patterns and similarities arising across the sample of DP users as a whole. Based on the information gathered in the previous stages, comparisons focus on: a) how the experience good nature of care impacted users' decisions; b) the differences in satisfaction with the care received derived from the possibility to choose the carer and influence how and when care is received; c) other factors that might have impacted the decision over how to spend the DP and the subsequent satisfaction with the care received. The use of Framework Analysis provides a flexible way to bring together information collected from several groups of interviewees (e.g. the DP users), by summarising

information and facilitating the comparison between the three subgroups of users of DPs (see section 5.2 below).

5.1.3 SELECTION AND RECRUITMENT OF LOCAL AUTHORITIES AND CARE MANAGERS

For reasons of logistical convenience for the implementation of the fieldwork, the LAs that were shortlisted to take part in the study were located in greater London. The initial objective was to have just one LA with a large enough number of older DP users willing to participate in the study. This would have ensured that each of the three groups would in principle have benefited from the same range of choice mechanisms, as LAs have some leeway as to the eligibility criteria for accessing DP. They would have undergone similar processes when in contact with their local authority (e.g. in terms of advice and counselling received) and would have been affected by the same market conditions (e.g. as to the available providers). Taking users residing in the same LA would make it easier to isolate the effect that the different choices have on users' experience with care as to *from whom* to receive care – the main differentiating aspect between the three groups.

LAs were first shortlisted for contact based on three criteria: highest absolute number of older DP users; low eligibility threshold for publicly-funded adult social care support; and high share of DP users among older users of care. The first two criteria were aimed to ensure that the pool of potential interviewees would be large enough, also accounting for their health condition, and that the probability of recruiting the necessary number of interviewees would be greater. In conformity with this, LAs were to be shortlisted among those having at least 200 older DP users, as this was considered to be a reasonable pool from where to draw the sample of DP users, and among those whose eligibility threshold was set as “moderate”. The third criterion – high share of DP users among older users of care – aimed to ensure that the selected LAs would have been committed to increase the take-up of DPs and would thus be more amenable to take part in the study. For this purpose, shortlisted LAs would ideally have a share of older DP users around the national average of 12.5% for 2011/2012 (including also those receiving a mix of DPs and LA-managed PBs – see Table 3.4 in Chapter 3), which was the latest available data at the time the LAs were selected.

An initial search on the internet and official LA documents (e.g. brochures) on the eligibility threshold for PBs revealed that the majority of LAs had set this for “substantial” or “critical”. As a consequence, it was decided to focus on the other criteria for the selection of LAs. Based on data from the NHS (2013) NASCIS Database, the fifteen London boroughs where the absolute number of older DP users was the highest at the time of data collection ranged from

Tower Hamlets with 215 to 955 in Barking and Dagenham. In relative terms, the share of DP users among all older users of care among the same fifteen LAs ranged from 7.4% in Havering to 27.7% in Barking and Dagenham. The official responsible for Adult Social Services in each of these fifteen LAs were contacted by e-mail, post letter and later by phone and permission was sought to carry out the study in their boroughs, with the collaboration of their staff (see example of invitation letter used in Appendix A). Four LAs answered positively and a meeting took place with an official from each LA to present and debate ways to carry out the study and gather further information on DPs in each LA. One of the LAs declined to participate after the meeting, explaining that a similar study was currently under way in that borough. The three remaining LAs accepted to take part in this study and agreed to indicate a member of staff to be responsible for liaising with the researcher. The absolute number of older DP users in the three participating LAs ranged from 220 to 390 and their share of total older users of care ranged from 9.7% to 18.3%.

As stated above, it was initially deemed desirable to conduct the study in just one LA. As the fieldwork began in LA#1, however, it quickly became obvious that circumscribing the study to just one LA would not yield a sufficient number of interviewees. It was thus decided to include all three LAs that had accepted to take part in the study. This raised the risk that expressed differences between interviewed users would be linked to differences between LAs (e.g. differences in eligibility criteria, in available services, regulations for the use of DPs, etc.), thus confounding the results. To minimise this risk, detailed background information on each LA was collected and special attention was paid to the geographical clustering of answers in the analysis stage of the data. Conversely, having users from three different LAs would likely ensure some diversification of the sample and could thus allow for a deeper understanding of interdependencies between factors impacting choice and for a wider range of these factors to be identified (Ritchie, Lewis, et al. 2003).

In order to collect the most detailed background information, the study aimed to carry out interviews with at least three members of staff from each LA or members of staff from support agencies. All three LAs were asked to indicate three members of staff to be interviewed or support agencies to be contacted (see section 5.1.4 for details on how the data were collected). The selection of members of staff to interview was not random, but purposive, i.e. LAs were requested to include members of staff with different levels of responsibility in the LAs' adult social care services (a senior manager of adult social care services, an official responsible for commissioning and a frontline staff member directly in contact with users of DPs) and therefore potentially with knowledge over different areas

related to DPs (e.g. referral and assessment, commissioning, etc.). All the interviewees were, however, directly involved with PBs and DPs. The profile of the interviewed staff was discussed and agreed beforehand with the researcher. Information on the study and aims of the interview were provided by the researcher (see information sheet for LA and support agency staff in the Appendix B) and this was passed on to the prospective LA or support agency staff interviewees.

A total of nine semi-structured face-to-face interviews with staff members of the three participating LAs and support agency were carried out prior to the interviews with older DP users. All potential interviewees indicated by the LAs agreed to take part in the study. Interviewed staff members included senior officials for adult social services, social care workers directly involved in the assessment and support procedures of older users of DPs, and a staff member from an independent support agency (see section 6.1 for more details on the profile of the interviewed LA staff). In LA#2, only two staff members were interviewed, but this was deemed sufficient as a social worker would be accompanying the interviews with older DP users and was thus available to provide contextual information as well. Besides these eight LA staff members, in LA#3, one additional staff member from a support agency indicated by the LA was also interviewed, which means that a total of nine interviews were carried out with what is generically termed as care managers. Whenever necessary, follow-up information was gathered via e-mail or face-to-face contact with the LA staff member responsible for liaising with the researcher.

5.1.4 SELECTION AND RECRUITMENT OF OLDER USERS OF DPS

The planned sampling procedure involved using purposive sampling (Marshall 1996) to recruit a total of 30 older DP users, although it was recognised there may be differences between them depending on how they had deployed their DP. The initial aim was to allow for some heterogeneity within each group in order to explore the impact of the relational nature of long-term care and the concept of user as co-producer of care across different types of people within each group. While allowing for some heterogeneity, quotas or other selection criteria (e.g. age, gender or socio-economic condition) were not imposed beyond the use of DPs, as this could only be achieved at the expense of larger samples (Ritchie, Lewis, et al. 2003). Given the time and resource constraints involved, this was not deemed feasible. It is worth stressing here that in line with the qualitative research methods employed in this study, the individuals sampled for the study were chosen “because they typify a circumstance or hold a characteristic that is expected or known to have salience to the subject matter under study” (Ritchie, Lewis, et al. 2003, pp.82–83). Rather than aiming to achieve a

representative sample of the users of DPs, the sampling procedure followed in this study is thus deliberately non-probabilistic as individuals were chosen to typify particular circumstances or characteristics of groups of users of DPs. Initially, the age threshold of potential older users of DPs to be interviewed was set at 65 years or older (a commonly used threshold to define “old-age”), but this threshold was later expanded to include 60 years and older in order to increase the pool of potential interviewees. This, however, does not impact the scope of the study as being focused on older people.

The participating LAs were initially asked to shortlist potential interviewees among their older DP users, whose cognitive capacities allowed them to understand the objectives of the study and give informed consent to participate in the study. In order to minimise recall bias, particularly given the frailty of some older DP users, potential interviewees were limited to those that had recently (in the past year) been assessed and provided with DPs for the first time. A further constraint was that DP users would be native English speakers, so as to minimise any difficulties arising from communicating with frail older people in a foreign language. This mostly excluded users from an ethnic background from the sample. All three LAs had set relatively high eligibility thresholds, providing PBs only to individuals assessed in the *Substantial* or *Critical* levels of the Fair Access to Care Eligibility Criteria, leaving out those with *Moderate* or *Low* needs. This meant that most interviewees were very frail, which influenced the number and profile of interviewees that could potentially take part in the study. In order to widen the pool of shortlisted potential interviewees, it was deemed necessary to expand the above described profile of potential older DP users to be interviewed, to include also older DP users with varying degrees of dementia. This raised the issue that users with dementia might not fully understand the objectives of the study and might not give informed consent to participate. A decision was therefore made to explain the objectives of the study to their close relatives and seek signed consent from these relatives to be interviewed as proxy respondents.

The use of proxy or surrogate respondents in qualitative research raises a number of questions, namely as to their reliability when questioned about sensitive, personal or highly subjective matters relating to the person on whose behalf they are being interviewed (Kaye 2007). This is particularly the case when proxy respondents are themselves the PA. In this case, the risk that the interests and views of PAs may not always coincide with that of users is substantially higher. Even when proxies were not the PA, they were often co-residing with users and were sometimes the main informal family carer and therefore their accounts also included reflections on their own interests in the identity of the carer and the delivery of care.

With this in mind, proxy respondents were probed to reflect not only on their own choices, but also on what they understood to be the preferences and choices of the service users so that whenever possible the two could be distinguished. As all proxy respondents were close relatives, and often co-residing relatives, they were likely to know the service user well and to have discussed preferences with the user before the decline of her or his cognitive ability.

The use of proxy respondents is not without its shortcomings (see section 7.4 for a discussion of the caveats involved) and to minimise the risk of confounding results a number of procedures were put in place. Firstly, it was possible to ensure that interviewees with only mild dementia were also present during the interviews and probed about their views. Secondly, as mentioned above, all proxy respondents were either co-residing or close family relatives so as to improve the consistency of proxy interviewees' answers (Lee et al. 2004). Furthermore, it can be argued that choice in the context of dementia is often either a shared decision between the user and the carer/relatives or a deferred decision, taken by relatives in the case of more severe cases of dementia, as the user might have limited consumer sovereignty (Eika 2009; Glendinning 2008). Thirdly, special care was taken in making sure that fewer proxies were also the paid PA of the user. Finally, users with advanced stages of dementia were contacted only as a last resort in order to minimise the share of interviews conducted with proxies (see section 5.1.5, below).

In LA#1, the shortlisted DP users received an invitation package sent by post by LA staff. The invitation package contained information on the study and a return consent form to participate that DP users were requested to sign and return to the researcher by post using a pre-paid envelope, indicating a contact number or address for further contact to agree on an interview date and place (see invitation package in the Appendix C). Upon receiving the return consent form, the researcher contacted the potential interviewees to provide further information on the study and agree on a date and place for the interview to take place. In LA#2 and LA#3, the shortlisted older DP users or their relatives (e.g. in the case of users with dementia) were contacted directly or by phone by the LA staff who explained the study, handed out an information sheet with information on the study prepared by the researcher, and requested permission from users to be interviewed. In these cases, whenever users gave their consent to participate, LA staff agreed on a date and place for the interview to take place and only then was this information passed on to the researcher. Throughout the process, the confidentiality of the identity and contacts of each DP user *vis-à-vis* the researcher was maintained. Until the moment potential interviewees accepted to be contacted (LA#1), or

agreed with LA staff to take part in the study (LA#2 and LA#3), the researcher was not knowledgeable of the identity or contact of shortlisted users.

In LA#2, interviews were part of the LA's care quality monitoring process of DP users. For that reason, a social worker accompanied the researcher and was present during the interviews, with the interviewee's consent. Embedding the interviews in LA#2's care quality monitoring process of DP users was an essential condition for the interviews to take place in the first instance. On the one hand, this meant that the presence of the social worker might have impacted interviewees' responses, even though they were free to express their views and often presented critical views of LA#2's services (see section 5.3 on the ethical implications). The potential for any negative impact on the interviewees' ability to express themselves was also limited by the fact that the social worker had not been involved in the assessment or counselling procedures. The social worker belonged to the unit within the LA that was only charged with monitoring quality and safeguarding issues. On the other hand, the presence of the social worker ensured that the terminology used throughout the interviews was accessible and understandable to the interviewees. As most interviews in LA#2 took place first, this was also important to make the terminology precise and understandable for the subsequent interviews. The social worker also provided invaluable information on each interviewee's background for the field notes.

Response rates varied among the three LAs, but were higher for the two LAs that contacted potential interviewees directly than for LA#1. In the latter case, only 1 out of 12 DP users that received the invitation package agreed to take part in the study after contacting the researcher to set up a date and place for the interview. A second person declined to participate for health reasons. In LA#2 and LA#3, respectively, 10 out of 37 and 13 out of 41 shortlisted users agreed with the LA staff to take part in the study and a date and place for the interview were scheduled. In LA#2, one other shortlisted DP user agreed to take part in the study, but was subsequently unable to participate due to his/her deteriorating health condition. Of all those who answered, no interviewee expressed any reservation in taking part in the study at any point after contacting the researcher. In total, it was possible to conduct twenty four interviews with DP users aged 60 and older or their proxy respondents that agreed to take part in the study.

As mentioned before, it was deemed desirable to have a diversified sample regarding the use of DPs (i.e. hire a PA or purchase care from a home care agency) so as to allow within-sample comparisons at the stage of data analysis. Achieving this could have proven difficult as only LA#3 had some knowledge of how DP users were deploying their DPs (paying PAs or

purchasing care from home care agencies) through the regular check-up visits carried out by their brokerage team. For the most part, only after the initial contact by LA staff (LA#2 and LA#3) was it possible to match each potential interviewee with one of the three groups. In the case of LA#1, it was only during the interview that the researcher could establish with certainty the mode of deployment of the DP. The uncertainty as to the size and composition of each of the three groups was therefore something inherent to the sampling process and something that the relative low response rates observed could have compounded on. Despite this, it was possible to have a relatively balanced distribution of interviewees among the three groups and thus use them as a typology in the analysis stage (see section 6.2).

5.1.5 DATA AND METHODS FOR DATA COLLECTION

Interviews with LA and support agency staff

The interviews with staff were preceded by data collection from secondary data sources such as LA websites, brochures and other available information on the general process of assessing and referral under PBs, as well as the regulations set in place for this benefit. The objective of interviews with LA and support agency staff was thus to consolidate and improve the information gathered on the regulations and procedures applied to PBs and DPs in each of the selected LAs. Furthermore, it also aimed to establish whether each LA had a large enough number of providers to be considered as a relatively competitive market.

Before each interview, the researcher explained the aims and overall design of the study as well as the subjects to be addressed in the interview. Potential interviewees could ask questions and clear doubts before signing consent to participate and have their interview digitally recorded (see consent form to participate in the Appendix D). In LA#3, research governance requirements made it impossible to digitally record the interviews with staff members and thus extensive notes were taken during the interviews. Each interviewee was also given the option to stop the interview and withdraw from the study at any point without any need for justification. All staff interviewed thus agreed to take part in the interviews.

As mentioned above, a total of nine semi-structured face-to-face interviews with staff members of the three participating LAs and a staff member from a support agency operating in LA#3 were carried out previously to the interviews with older DP users (see topic guide in the Appendix F).

All interviews took place in the workplace of the LA or support agency staff and lasted between 30 and 60 minutes. Interviews were carried out between February and May 2013.

Interviews with staff from LA#1 and LA#2 as well as the support agency from LA#3 were digitally recorded. An extensive summary of relevant information was transcribed and sent back to interviewees who were asked to check the accuracy of the contents. As it was not possible to digitally record the interviews with staff in LA#3, in this case the contents of the extensive notes taken during the interviews were also organised as summaries and shared with interviewees to check for accuracy. Follow-up contacts by e-mail or face-to-face to further clarify the information gathered were also carried out when necessary in all three LAs. The researcher carried out all interviews.

The semi-structured interviews focused on the process of assessing and referring users to care options, as well as contextual information on the local care market, namely qualitative information on the number of providers operating in each borough, in order to assess the competitiveness of the local market. The interviews with LA and support agency staff also allowed for the fine-tuning of the terminology to be used subsequently in the interviews with older DP users. Interviews with LA and support agency staff covered the following topics (see topic guide for the interviews in the Appendix F):

- The factors taken into consideration in the assessment process for PBs.
- Available options for those deciding to take their PB as a DP and what support is made available for those recruiting PA or purchasing services from home care agencies (e.g. lists of agencies operating in the local authority). Clarification of the role of LA frontline staff in this process.
- Steps taken by the LA to promote any type of option (e.g. PAs or home care agencies) and to explicitly foster providers' responsiveness or the availability of PAs.
- Information on the local care market: such as number and diversity of providers and care options available, possibility for home care agencies to directly supply care to DP holders, evolution of the care options offered to DP users.
- Views on how and why users that take DPs make their choice in terms of hiring a PA or acquiring services from home care agencies, namely on the factors impacting one or the other choice.

Interviews with older users of DPs

Before carrying out the interviews, guidelines and prompts were discussed with LA staff of each participating LA as part of research governance requirements, i.e. to ensure that potential interviewees would not be distressed by the nature of questions, and to ensure that

proper and understandable terminology was used. Guidelines were also checked for the presence of professional jargon or acronyms that could render comprehension of questions or subjects by potential interviewees more difficult.

Immediately before each interview with older DP users or their proxies, the researcher explained the aims and overall design of the study as well as the subjects to be addressed in the interview. Potential interviewees (whether DP users or their proxies) could ask questions and clear doubts before signing the consent form to participate (see consent form to participate in the Appendix E) and have their interview digitally recorded. Each interviewee or proxy was also made fully aware of the possibility to stop the interview and withdraw from the study at any point without any need for justification.

A total of twenty-four in-depth semi-structured face-to-face interviews with users of DPs aged 60 and older, or their proxies, were conducted between March and May 2013. The first seven interviews were carried out in the second week of March, in LA#2, and were used to pilot the interview guidelines and terminology used. Subsequent interviews took place from the last week of March 2013 onwards.

The pilot interview confirmed the overall adequacy of the guidelines and terminology used. The only changes that resulted were a slight simplification of the prompts used in the guidelines and minor changes to the terminology. These mostly served the purpose of facilitating the flow of the subsequent interviews. The changes to the terminology were also informed by valuable input from the social worker from LA#2 that accompanied the pilot (and subsequent) interviews in that LA. Changes introduced were sufficiently minor to allow data from pilot interviews to still be used in the analysis. Indeed not only did the themes covered in the guidelines remain unchanged, but also the presence of the social worker in the pilot interviews ensured that terminology was always understandable to interviewees.

All interviews took place at the user's home, with the exception of one interview that took place in the home of the proxy respondent without the user being present. Interviews lasted between 30 to 70 minutes and were digitally recorded. Field notes were taken during and immediately after each interview to supplement recorded information, namely information on interviewees' background (e.g. family or health situation) gathered immediately before or after each interview from the LA staff accompanying the process. The researcher carried out all interviews.

Of the twenty-four interviews, nine were carried out with the older DP user alone and four had the presence of the spouse and the DP user. Only two interviews had the proxies as the main respondent without the presence of the DP user; and finally nine interviews featured proxies as the main respondent in the presence of the DP user.

In the four cases where in practice couples were interviewed (DP users and their spouses), the initial stages of the interviews served to ascertain the role of each partner in the decision-making process regarding DPs. There were no reported differences of opinion between DP users and spouses in the four cases concerned. In the case of interviews with proxies in the presence of DP users, it is worth bearing in mind that even though DP users were present, their health status (e.g. advance stages of dementia) sometimes precluded any meaningful input from DP users to the interview. In the latter case, the initial stages of the interview served to ascertain:

- i. Whether the DP user was already in his/her present condition at the time when choices regarding the DP were being made. This helped to determine to what extent the DP user had been involved in the relevant decisions.
- ii. Who was responsible for the decisions regarding the DP. This aimed to establish who had had agency over the decisions and whether the proxy was thus a relevant person to be interviewed.
- iii. How and when the DP user had expressed his views and preferences regarding care and what these were.

Whenever the DP user was cognitively able to participate in the interview together with the proxy respondent, the above steps were nonetheless also taken and the interviewer made sure that the DP user was prompted to also give her/his views on the themes more closely related to her/his experience, such as the relationship with the carer. Although there were no reported differences of opinion between proxies and cognitively able DP users, these cannot be completely ruled out. Proxies provided care to DP users in all cases, but only in two interviews were proxies also the paid PAs of the DP users. Despite the precautions described above to ascertain the degree of participation of DP users in the decision-making process and to collect her/his views, it is nonetheless likely that the dual role of proxy interviewee and PA could result in confounding accounts of the choices made regarding the use of DPs. This is one of the reasons why users with dementia and their proxies' responses merited a section of their own in the analysis of findings (see section 6.6 in Chapter 6).

Each DP user or proxy respondent was prompted to recall his/her experiences regarding the decision-making process when the choice of care was originally made; how the on-going care relationship had evolved and current satisfaction with care received. More specifically, DP users or proxy respondents were prompted to provide information on the following themes (see topic guide in the Appendix F):

- The search process that led to the decision to hire a PA or acquire care services, namely what characteristics of the PA (in the case of “employer + relational” and “employer” users) or the agencies (“purchaser” users) were sought and valued the most; what information was used (e.g. how important was the feedback from other users or referral from care managers); and how they came into contact with the chosen PA or agency.
- The actual choice made and in particular the reasons why users eventually settled for their final choice.
- The negotiation of care provision, for example, choice of timing, contents and nature of care provided.
- The importance of relational aspects of care, namely how users defined their relationship with their carers, how this relationship evolved over time and how they would perceive a change of carer – either if imposed by a third party or if they were unsatisfied with the current arrangement.
- Satisfaction with care and relationship with the PA/agency. This related in detail to the aspects that most contribute to the users’ satisfaction and those that they would like to change, thus providing more information on the aspects of care that users value the most. Users were also asked how the relational aspects of care, on the one hand, and the increased agency in defining the care package, on the other hand, impacted their perceived experience with care.

5.2 METHODS FOR DATA ANALYSIS

The analytical process began with the gathering of data, i.e. with the first interviews with DP users, employing what Miles and Huberman (1994) coined as “interim analysis”. This included reading field notes and reflecting on the contents of the interviews (while transcribing the first interviews) and thus starting the process of checking the data to identify emerging topics. Some of the topics or ideas could be followed up in subsequent interviews, a process typical of qualitative methods where the researcher can probe for emerging topics even during data collection and thus adapt that same process of data collection.

It is worth bearing in mind that although LA staff interviews took place before the interviews with DP users and were also mostly digitally recorded, these interviews with staff were neither transcribed nor coded and were also not analysed using the Framework Analysis. There were several reasons to support this decision. From the beginning LA staff interviews were only meant to provide background information on the local care markets that could subsequently be explored in the data. For example, patterns or clusters emerging from the data were checked against the information collected at each LA's local care market in order to verify whether these clusters actually reflected contextual differences between LAs (see section 6.2.1 below). Although LA staff were purposely selected for the interviews, the sample and data gathered were not systematised in a way that allowed them to be analysed using qualitative methods in a standalone empirical study. For example, the questions posed to LA staff (see Appendix F) were differentiated according to their role in the LA and in the process leading up to the provision of DPs. The staff interviewed included officials with sometimes dissimilar roles in each LA (see section 6.1). For example, it was only possible to interview a staff member from the independent support agency commissioned to provide information and support in LA#3 and not in the other LAs. Furthermore, as indicated above, in LA#3 interviews with LA staff could not be recorded (only the interview with the staff member from the independent support agency was digitally recorded). This also limited the in-depth analysis of their contents and inclusion in a standalone empirical study together with the interviews from the other LAs, which were digitally recorded.

5.2.1 MODEL FOR ANALYSIS

The analysis of the data transcribed from the interviews with DP users and their proxies was carried out using Framework Analysis (Ritchie, Spencer, et al. 2003). This methodology provides a flexible way to bring together information collected from the three groups of interviewees, by summarising information and facilitating the comparison between the three groups of users of DPs. The process of using Framework Analysis involves four phases: familiarisation with the data collected and coding; summarising data by way of thematic charts; making use of these charts to identify possible patterns and associations; and from there deriving conclusions.

The familiarisation with data was greatly enhanced by re-listening to the digital recordings and transcribing the interviews. The majority of the interviews were transcribed by the researcher and the remaining transcripts were checked against the digital records of the interviews for accuracy. The fact that the same researcher conducted all interviews also greatly contributed to the familiarisation process.

Based on the previous literature review and on the hypotheses, a thematic framework or index of themes was constructed and this was then used as the basis to code the transcripts (Miles & Huberman 1994). While there is always the risk that data may be forcibly fitted into this pre-existing structure, this more deductive approach allows for the analysis to be built on existing evidence and theory (Bradley et al. 2007). To accommodate for this risk, the index of themes was left very open with only a limited number of themes. The thematic framework thus retained sufficient flexibility so as to allow for modifications as the analysis progressed. For example, it became clear early on in the process of conducting interviews that many interviewees had had previous experiences with LA-managed care. This was not only central to their experience with care and their understanding of what they valued in care, but could have also impacted their subsequent choices. Therefore a theme on “Circumstances of care” was added to the thematic framework²⁸.

For the coding or labelling of the data (Ritchie, Spencer, et al. 2003), each sentence and paragraph was read and its content examined in order to understand “what is being said here?” and a code or label emerging from the data was assigned to blocks of text (phrases or paragraphs). Each assigned code would then be placed on the thematic index. As more transcripts were analysed, increasingly fewer new codes arose from the data. This reflected the theoretical saturation of the data (Guest et al. 2006) as new observations produced little additional variation. Already existing codes would be assigned instead. Each block of text could have overlapping codes, for example, in an excerpt referring to the choice of carer – coded “choice of who” – the interviewee could also be referring to something about the relational aspects of care – labelled “relational”.

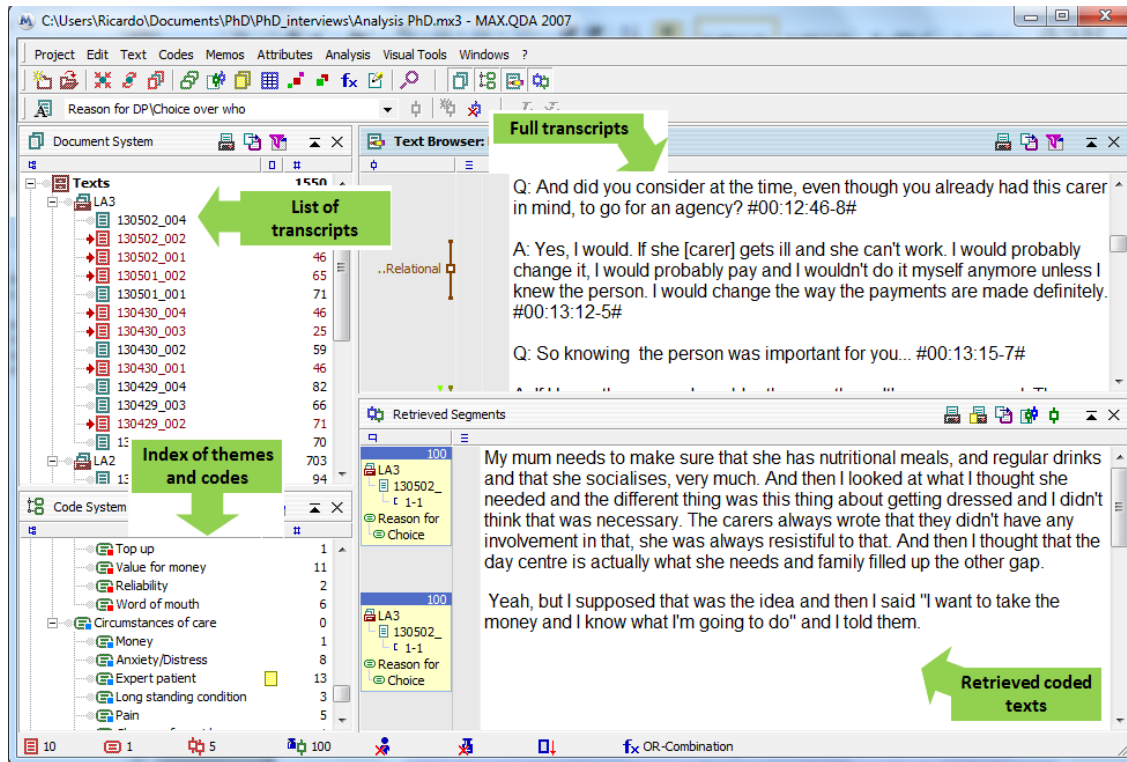
In the process of coding, the labels were compared and when deemed adequate grouped together in wider categories, which in turn were then further compared to see whether other clusters of codes would emerge. Throughout the process, notes were taken not only on the definitions of certain codes, but also on the rationale for the clustering of codes into wider categories. As an example, interviewees referred to being able to share intimate stories and insights on their personal or family life with their carers and how they valued their carers not sharing this information outside their home. This was initially coded separately as “Maintaining discretion”, but subsequently was clustered together with the code “Trust” that included until then only more literal references to confidence and trust (e.g. referring to

²⁸ Subsequently this theme was merged with other themes to form the theme “Decision leading to DPs” and for this reason the theme “Circumstances of care” is not presented in Table 4.1.

situations such as entrusting the carer with the house keys or with finding a replacement carer). A note was thus inserted explaining that the code “trust” included also this sharing of personal information. While one or another code may have been merged or clustered, during the process of coding it was considered more advantageous at this stage to keep a larger and more detailed thematic index rather than a smaller set of codes. This approach reflected the fact that coding was an initial stage in the analysis process, but it also aimed to prevent that early merging or clustering of codes would forcibly condition the subsequent process of analytical interpretation of the data.

The process of coding was carried out with the software package MAXQDA. Once the transcripts and accompanying notes were uploaded, the use of software such as MAXQDA greatly facilitated the task of managing the data. It allowed, for example, for codes to be attributed to selected texts, for codes to be easily merged or divided (with accompanying notes) and then for excerpts to be retrieved according to codes and/or attributes of observations. The three types of DP users utilised in this study or any other attributes deemed interesting for analysis were also subsequently systematically explored in the data (e.g. living arrangement, health condition, proxy respondent, etc.). Figure 5.1 displays a screenshot of MAXQDA working environment depicting the various elements from MAXQDA signalled in green boxes, namely: the list of transcripts, the index of themes and codes, the retrieved coded texts (by code and/or attribute) and the selected full transcript with the codes assigned on the right-hand side.

Figure 5.1 – Elements of MAXQDA working environment



Once the data had been coded, a thematic chart or matrix for themes was constructed with Microsoft Excel, as displayed in Figure 5.2 as an example. Each Excel spreadsheet corresponded to a thematic chart covering a number of themes, displayed in separate columns, with each row corresponding to an interview or observation with the main attributes of the individual depicted in the first cell. Each cell then synthesizes the information pertaining to each particular theme and individual. The cells may include expressions from interviewees (albeit not lengthy quotations) or notes to places in the transcripts that are considered important for detailing a particular point and could thus be important in subsequent analytical steps.

Figure 5.2 – Example of excerpt of the thematic matrix “Feelings with carer” in Excel

	A	B	C	D	E	F	G
1	Feelings with carer	3.1	3.2	3.3	3.4	3.5	3.6
3	User	Initial feeling	Change/build of rapport	Reciprocity	Relationship	Managing carer	Boundaries
4	Anonymised_ID_code Male, 71 Agency, physically disabled		Asked to do more things as they get to know each other.		Friendliness. One or so he can call. Dignity.		Some ex-carers till ring him up to see if all OK.
5	Anonymised_ID_code Female, 81 Agency, physically disabled		You learn to trust and to confide.		Carer is honest, reliable, she can confide on her.	Amenable carer with tasks.	
6	Anonymised_ID_code Female, 71, PA not known, physically disabled	With some carers she had a "I like her" feeling.	You become friends. You "learn" to trust and are able to confide on the carers.	Give and take in terms of the times - earlier in today, living earlier tomorrow. Flexible arrangement also when the carer not feels well. Concern over carers being exploited with	You become friends, but you should hold back a bit. Recognises that with agency staff it's different - more distance. She defends carers - gave chance to one that had mental issues and regretted it. You learn to trust.	Managing being soft and hard with carer on how to do tasks.	Recognise that becoming friends can be a barrier. That you should hold back. Has paid and shared meals outside home with carers. With agency staff there is more of a distance. Do not talk about other clients. Carer attended funeral of her husband. Share

Note: The term “Anonymised_ID_code” replaces the actual individual anonymous code that each user cell has, so as to protect the anonymity of interviewees in this screen shot.

The matrices and the headings correspond respectively to the themes and codes of the thematic index in some, but not all cases. As Ritchie, Spencer and O’Connor (2003, p.230ff) refer in their guidelines for Framework Analysis, this reflects the maturing of the analytical process as new themes and associations between themes emerge during the coding process and one begins to interpret the data. As an example of this process of analytical maturation, there were initially codes pertaining to the *how* interviewees described their current relationship with their carers (e.g. “friendship”, “professional”, “like family”, “trust”) and codes pertaining to relational dimensions in making choices (e.g. “burden on family”, “neighbours”, “power”). As the analysis progressed, it became clear that the majority of codes such as “friendship” or “friendliness” captured the nuances of a wider heading concerned with “relationships”, while codes such as “burden on family” or “trust” were more akin to caring as a power relationship – a heading connected with the literature (Kittay 1999) (see Chapter 2). In another example, the thematic chart relating to experiences with care came to encompass not only codes referring to the identity of the carer (e.g. “choice over who”, “continuity”) or the care process (e.g. “choice of what”, “knowledge of needs”, “flexibility”), but also a number of codes on how users reflected on the impact of DPs on themselves (e.g. “assertive”, “self-aware”) captured by the heading “changing self”. The construction of the thematic matrices thus increasingly involved more abstract concepts and inductive theory-building analysis. The structure of the matrices and the headings for each are depicted in

Table 5.1. Again, this was an iterative process as the contents of the headings were re-read, reflected upon and questioned as new associations between headings or new questions emerged.

Table 5.1 – Thematic charts and headings for analysis of qualitative data

Thematic matrices	Headings
Decision leading to DPs	Trigger Previous arrangements Broad context Feelings Expert patient Important people Dissatisfied with agency Dissatisfied with LA/process Reason for choice
Search and choice agency/carer	Screening and signalling Dimensions of care Decision Accompanied choice Relational Experience good Switching costs
Feelings with carer	Initial feelings Change/building rapport Reciprocity Relationship Managing carer Relationships as power and boundaries
Experiences with care	Managing benefit Who (non-relational dimensions) Relational Time Tasks Changing self Satisfaction
Dementia	Family carer User as co-producer of care Homely environment Rapport with carer Time Needs

The subsequent analysis involved using the matrices to probe for patterns, associations and clusters with a view to develop explanatory accounts and find causal links. In the context of Framework Analysis, it is common at this stage to search for typologies (e.g. clusters of individuals) as part of the analytical process (Ritchie, Spencer, et al. 2003). In the case of the

present study, however, a typology had been established *ex-ante* – i.e. the three types of DP users referred to before – and were thus used throughout the whole qualitative analysis.

Although a typology had been established *ex-ante*, other possible associations between the themes and attributes of the individuals were, nonetheless, explored in the data to examine whether certain factors had any effect on the findings. The possible associations explored were the following. As the interviews were expanded to include three LAs, rather than only one as initially planned, the patterns emerging from the data were analysed to check whether they reflected the clustering of observations among LAs. Some of the findings were checked for associations with particular attributes such as age, gender, living arrangements and other social support networks, characteristics of the carers such as their tenure, health condition of interviewees and type of interviewees (users themselves or proxies). For instance, the analysis explored whether individuals living alone or with limited contact with family or acquaintances had different types of relationships with their carers. This included not only comparing different types of relationships with the characteristics of users – using the matrices depicted above (see Figure 5.2) – but also analysing their narratives to have a better understanding of possible factors that could be associated with particular relationships. For example, this included checking whether users with closer relationships with carers felt lonelier or more disheartened. Similarly, the reciprocal exchanges observed in some caring relationships were compared with information about the tenure of the caring relationship with the paid carers retrieved from the interview transcripts. One issue in particular deserved careful consideration: the possible association between certain themes and the use of proxy respondents – an issue that will be more thoroughly discussed in section 6.4. While a wide range of factors were examined for possible explanatory effects on the findings, two could not be thoroughly analysed: income and care intensity as measured by the number of hours included in the care package. Both were deemed confidential and not provided by the LAs and the interviewees were not directly asked about the former. In addition, they often expressed less than full knowledge of the number of hours that their DPs entitled them to.

The purpose of the above described systematic exploration of possible associations between themes and certain attributes of interviewees was not only to identify commonalities and patterns, but also to explore the exceptions, the outliers and the diversity in the data. This is something which qualitative methods are particularly suited to account for (Lewis & Ritchie 2003). This process sought to strengthen (or rule out) possible explanations through the study of possible associations and exceptions. The fact that some factors had no explanatory effect could be equally salient to the analysis of the findings and thus the importance of

exceptions as well as associations. The outcomes of this analytical process are detailed in the findings (Chapter 6).

5.3 ETHICAL GOVERNANCE

The study design was submitted and received ethical approval from the Department of Social Policy and Social Work Research Ethics Committee of the University of York prior to initiating the contacts with the LAs. Meetings with officials of each of the participating LAs took place before the start of the study to discuss any research governance requirements from the LAs and also to ensure that procedures added as little extra workload to LA staff as possible. As interviews were likely to take place in people's own homes, the interviewer undertook a Criminal Records Bureau (CRB) check and this information was shared with the LAs and interviewees.

The anonymity of potential interviewees vis-à-vis the researcher was maintained until the moment they communicated to the LA staff that they would be willing to participate in the study (LA#2 and LA#3), or used the stamped return consent form to express their consent (LA#1) (see section 5.1.4).

Before each interview, signed permission was obtained to participate in the study and to digitally record the interviews. Interviewees were also assured of confidentiality, anonymity and the right to stop the interview at any point. Interviewees were also informed that information provided by them could be disclosed to the LA if at any point during the interview it became clear that they were at risk or being harmed (see example of consent form in the Appendix E). In LA#2, the interviews took place in the presence of a social worker from the LA to comply with the LA adult social services' research governance requirements. Anonymity and confidentiality of the interviewees could therefore not be maintained in LA#2. The interviewees were made aware of this and gave their consent to the presence of the social worker. In LA#2, one of the interviewees reported a situation of financial abuse involving one carer in the presence of the social worker. The interviewee was made aware of the possible implications for the carer of disclosing this information and that the transcript of the interview would have to be made available to LA adult social services, to which the interviewee agreed.

The LAs were responsible for suggesting members of their own staff to be interviewed, in agreement with the researcher (see section 5.1.3). Interviewees were made aware of this before the start of the interview and accepted to participate nonetheless. The contents of

these interviews were not, however, at any point shared with the LAs. Furthermore, the anonymity of the LAs was also kept as each was assigned a code and special care was taken not to identify them through other means (e.g. when detailing their socio-economic background or using statistics on number of users – see Chapter 6).

To protect the anonymity and confidentiality of all interviewees, as well as that of third persons (e.g. relatives referred to during the interviews), names were not used in the interview transcripts (similarly digital recordings files were not named after the names of interviewees). Each interviewee was assigned a code used in all transcripts and excerpts, as well as in the analysis of findings (see Chapter 6) and dissemination of the study. The digital recordings and transcripts were kept on a computer with a password known only to the researcher. The hardcopies of the signed consent forms were kept in a locked cabinet. For the digital recordings that were not transcribed by the researcher, no identifying names were included in the digital files and an encrypted system was used to communicate with the professional transcribing company employed for this.

It was envisaged that interviewed DP users might become upset while talking about their experiences with DPs or that of their relatives in the case of proxy respondents. To minimise this risk, interviews with older people were carried out in their own homes and users were given the possibility to be accompanied by someone of their choice. In anticipation of interviewees feeling upset or having doubts regarding the functioning or use of DPs, advice from the LAs was sought before the fieldwork took place about available sources of support, as well as information and their contacts, so that these might be passed on to interviewees. Two interviewees showed signs of being upset during the interview. They were offered the possibility to stop the interview, which both declined, and to receive the contacts of the local support organisation, which they also declined, preferring to seek the support of their relatives.

This chapter provided a detailed description and discussion of the methods employed in this study, its aims and rationale, sampling strategies, data analysis and ethical aspects. It aimed to establish that the research conducted was as rigorous as possible given the available resources. The following chapter will present the findings of the empirical research.

Chapter 6 : FINDINGS OF THE EMPIRICAL STUDY

The two central tenets of the research carried out in the context of this thesis are, firstly, that relationships are an important dimension of caring; and secondly, that the user in long-term care is not only a passive recipient of services, but also a co-producer of care (see Chapter 2). From this follows that satisfaction with care received is likely to be influenced by who provides care – i.e. by the identity of the carer – as well as by how, when and what type of care is provided. The potential challenge arising from this is that long-term care is an example of what in economic terms is called an *experience good*. Users have difficulties in assessing ex-ante both satisfaction with relationships and satisfaction with the way care is provided.

Personal Budgets (PB) in England allow users of publicly funded home care services to opt for a cash Direct Payment (DP) and use it to hire a personal carer, including someone previously known to the user, or purchase services from a home care agency of their choosing. The review of the wide range of empirical studies on the experiences of users of DPs in England (see Chapter 3) showed that relatively limited attention has been paid to the relational and co-production aspects of care and how they impact the choices made by older people using DPs to hire PAs or purchase care services. In seeking to fill this gap in knowledge, the main research question of this thesis is therefore how and why users' experiences with care are affected by the decision to hire a personal carer rather than to acquire services from a formal provider (i.e. a home care agency). In this context, it is hypothesised that hiring a personal assistant (PA) rather than purchasing care from a home care agency could translate into higher user satisfaction via two possible pathways or hypotheses (see Chapter 4):

- By allowing the user to choose from whom to receive care, which matters to the user given the relational nature of long-term care;
- By widening the leeway afforded to users in defining what, when and how care is provided.

The above-stated research question was investigated using qualitative research methods to gather data – i.e. semi-structured interviews with users of DPs aged 60 or older – and to analyse them – through Framework Analysis (Ritchie & Lewis 2003) – as discussed in detail in Chapter 5. As part of the research method (Lewis 2003), three groups of users receiving

DPs that differ in the choices they have made as to the use of the benefit, were used as a typology to analytically compare the experiences of different types of users:

- The **relational users** or **relational-type users**, i.e. those that hired a PA previously known to them, who may have a greater leeway in defining the care they received by hiring and managing their own paid carers; while at the same time experiencing less uncertainty as to the experience good nature of the relationship component of care by hiring someone they previously knew.
- The **employer users** or **employer-type user**, i.e. those that hired a PA not known to them, who may also have a greater leeway in defining care they receive (they are also the employers of their own carers) and building a relationship; whilst facing uncertainty as to the identity of the carer.
- The **purchaser users** or **purchaser-type users**, i.e. those that acquire care services from home care agencies, who might face higher uncertainty over the relational aspect of care (choosing who) and possibly more limited possibilities to determine the care they receive.

The users from each of the above described groups interviewed in the context of this study were sampled among older DP users in three local authorities (LAs) from the greater London area that agreed to take part in this study (see Chapter 5 for more details on the selection of the LAs). The collection of data through in-depth semi-structured interviews took place between March and May of 2013. The present chapter presents information on the selected LAs and the findings based on the analysis of the interviews with older users of DPs.

The present chapter is organised in the following manner. The first section presents information on the three selected LAs. It draws on the data collected through desk research as well as through semi-structured interviews with care managers from each LA and one interview with a member of staff of a support agency. This section briefly describes the socio-economic conditions prevailing in each selected LA and depicts in more detail the characteristics of local care markets (e.g. number of home care agencies operating, type of contracts between the LA and home care agencies) and the conditions under which DPs are provided (e.g. assessment criteria and eligibility thresholds, constraints on the use of DPs). This description is made while maintaining the anonymity of the participating LAs. The second section succinctly describes and discusses the socio-demographic characteristics of the sample of older DP users interviewed for this study.

The subsequent sections three to five present the findings of the semi-structured interviews with older DP users and proxies around three main topics of relevance for the research question. Section three presents the findings on the initial process of choosing agencies or PAs. This includes the context that led to the decision to take DPs in the first place and whether relationships were a factor in the initial choice, for example, to what extent users wanted to choose acquaintances as their PAs to circumvent uncertainties around the identity of the paid carer. The fourth section focuses on the relational aspects of care, most notably how users defined their relationship with their carers (whether agency carers or PAs), how it evolved and how this impacted their experience with the care received and their choices. Section five analyses the narratives around the definition of tasks, times and schedules for the delivery of care, i.e. how different types of relationships entail different levels of opportunity to shape care (what, how and when). The analysis of findings in sections three to five begins by focusing on the main issues across the three groups, i.e. the main issues arising in the sample as a whole. It then proceeds to highlight similarities and differences between the three groups, as well as exceptions, that might contribute to the knowledge of the impact of the relational and experience good nature of care on the choices of older people. At the end of each section, the main issues arising from the narratives of users are summarised and placed in the wider context of the main hypotheses of this study. The purpose is not so much as to prove these hypotheses right or wrong, but as to help the reader make sense of findings in view of the main research question of this study.

Section six focuses on the narratives of one particular group of older users of DPs: those with some degree of dementia and their proxy respondents. This group is defined by its condition and particular symptoms associated with it and it includes users from the above described relational, employer and purchaser groups. This section also takes a closer look at the answers of proxy respondents and their implications for the analysis of the relational aspects of care. Finally, a seventh section briefly concludes and summarises the overall findings.

One final note on terminology and identification of excerpts from interviewees' narratives. Concerning the former, throughout this chapter, *PAs* refer to carers directly employed by users, whether acquaintances or not. Whenever there is the need to distinguish between PAs that were acquaintances from those that were strangers, this will be made clear in the text. The term *paid carers* refers to carers in general, whether PAs or those employed by home care agencies. Whenever it is necessary to single out the latter, these will be referred to as *agency carers*. Similarly, relatives or other acquaintances providing care informally (i.e. not employed as PAs) will be referred to as *family carers*. As for the excerpts from interviewees'

narratives, these will be accompanied by information on the place of residency (i.e. which of the participating LAs), gender, type of user (purchaser, employer or relational), age and when applicable whether the excerpt refers to a proxy with or without the user being present.

6.1 DIRECT PAYMENTS IN THE SELECTED LOCAL AUTHORITIES

The three LAs that agreed to take part in this study were all situated in outer London and had a population ranging from about 150,000 inhabitants to approximately 300,000, according to the 2011 Census (Office of National Statistics 2014a). Still according to Census data, the population of the three participating LAs was relatively older in comparison to greater London as a whole: LA#3 had about 16% of people aged 65 and older, while LA#1 had about 12% and LA#2 13% compared to 10.7% for London as a whole (Office of National Statistics 2014a). As for the ethnic composition of the population, LA#1 was mostly 'White British' with a sizeable 'White Other' population and very few inhabitants of other ethnical background. LA#2 was by far the most ethnically diverse with people with Asian background as the largest ethnic group (mostly from India, Pakistan, Bangladesh and other Asian countries besides China), while 'White British' accounted for a third of the population and 'Black African' and 'Other Whites' were also sizeable minorities. Finally, the older population in LA#3 was overwhelmingly 'White British' (close to 80% of its population) with 'Black Africans' as its second largest ethnic community (less than 10% of the population). According to several indicators displayed in the report *Focus on London 2010, Income and Spending at Home* (Walker 2010), such as equivalised median household income, percentage of households with equivalised household income below 15,000 GBP and housing prices (all data for 2009), LA#1 could be considered as a higher income LA, while LA#2 and LA#3 were close to the London average.

The interviews carried out with LA and support agency staff members (see section 5.1.3) provided detailed information on the profile and operating processes of adult social care services for older people in each of the LAs (Table 6.1). The eight LA staff members who participated in interviews included a senior commissioning official in LA#2, a senior responsible for adult social services in LA#1 and LA#3; and five social care workers directly involved in the assessment and support procedures of older users of DPs (two in LA#1 and LA#3 and one in LA#2). Furthermore, a staff member who supervised provision of information on DPs from the independent support agency commissioned to provide information and support in LA#3 was also interviewed.

Table 6.1 – Summary of information on DPs in the LAs participating in the study

	LA#1	LA#2	LA#3
Eligibility threshold	Substantial and critical	Upper substantial and critical	Substantial and critical
Deployment options	Purchase care from home care agencies; hire PAs; DPs can be managed by support agency.	PBs not yet implemented. Purchase care from home care agencies; hire PAs; ISF with home care agency managing DPs.	Purchase care from home care agencies; hire PAs; DPs can be held in pre-paid card with attached bank account.
Information	Support agency sets up care plan, acts as broker between user and home care agencies; liaises with payroll agencies. Directory of PAs managed by the support agency. Directory of all home care agencies, including those not contracted by the LA.	Support agencies in place to provide information and liaise with payroll agencies. No directory of PAs at the time of the interviews. Directory of home care agencies includes only those contracted by LA (1). Agencies under ISF set up care plan.	Support agencies in place to provide information and liaise with payroll agencies. No directory of PAs at the time of the interview. Directory of home care agencies includes only those contracted by LA (1).
Home care agencies	Four home care agencies have framework contracts with the LA (1), with DP users paying same rates as LA-managed users.	Four home care agencies manage ISF; Five agencies have block contracts with LA (1). DP users negotiate rates with home care agencies directly.	Fifteen home care agencies have framework contracts with the LA (1), with DP users able to purchase care from these agencies but at higher rates than users of LA-managed care.
Constraints on use of DPs	Unspent DPs assessed on a case to case basis. Tight control over employment of co-residing relatives as PAs.	Constraints on the ability to accumulate unspent DPs. ISF allows accumulation of up to 3 months of unspent DPs. Tight control over employment of co-residing relatives as PAs.	Unspent DPs to be returned to LA, unless accumulation is specifically authorised by the LA. Tight control over employment of co-residing relatives as PAs.

Source: Interviews conducted with LA and support agency staff.

Notes: (1) Refers to home care agencies contracted to provide LA-managed care.

Regarding provision of information on DPs to users, in LA#1 and LA#2 this is usually provided by LA social workers at the time of the assessment of needs. LA#3 has put in place a brokerage system which provides users with information about PBs after the needs assessment and establishment of a care plan. The brokerage team is also responsible for monitoring the use of PBs. In LA#1, users that show interest in hiring a PA are referred to a user-led organisation that has been contracted by the LA as the support agency. This support agency plays a vital role in setting up DPs. It is the support agency that is responsible for setting up the care plan together with the user after receiving information from the LA on the needs assessed and amount allocated to the user. Besides providing support with payroll, the support agency can also act as a brokerage agency (i.e. assembling support from several organisations, including volunteers) and it also manages a directory of PAs from where users in LA#1 can hire their paid carers. Alternatively, the support agency can assist users that wish to recruit their own PA or contact and purchase care from home care agencies. As housing prices were relatively high in LA#1, staff members were concerned that not many users had a chance to hire PAs locally, which meant that PAs had to travel from afar. Similarly, LA#2 and LA#3 have also contracted support agencies (in the case of LA#2 the support agency is also a user-led organisation) to provide information and support in hiring PAs or to liaise with payroll management agencies. These support agencies do not, however, manage DPs on behalf of the user, nor do they set up the care plan. There was not yet a directory of PAs available in either LA#2 or LA#3 at the time of the interviews²⁹.

PBs have been in place in LA#1 since 2009, date when PBs were extended nationwide. Regarding the *choice set* (Klein & Millar 1995) of users at the time of the interviews, LA#1 had also established framework contracts with four agencies contracted to provide LA-managed care. This means that these agencies are not guaranteed any volume of work and have to attract users, including those receiving DPs. To this end, older DP users in LA#1 can purchase care from these four agencies³⁰ at the same rates as users with LA-managed care, which is unlike the other two LAs. There is also a directory of other home care agencies operating in the borough, although quality is only monitored for those agencies currently under contract

²⁹ In response to perceived difficulties in hiring PAs, both LA#2 and LA#3 were in the process of setting up these directories at the time of the interviews.

³⁰ LA#1 actively promoted the rotation of agencies under contract, i.e. incumbent contracted agencies were purposely replaced after three years. At the time of the interviews, the incumbent user-led support agency had also not seen its contract renewed and although it would continue to operate in the borough, another support agency had been contracted by LA#1 to assist DP users.

with LA#1. LA#3 has also established framework contracts to deliver LA-managed care and DP users can purchase care from these agencies. However unlike LA#1, users pay the same (higher) rates as privately funded users when purchasing care from these agencies. DP users may, however, freely top-up their payments to get more hours of care. There were, at the time of the interview, fifteen agencies under contract with LA#3, and only information on these was available in a directory of home care agencies. DP users in this LA could also choose to have their DPs deposited into a LA-held bank account with an attached pre-paid card. They could then use this card to make their payments for care. As for LA#2, it had not yet implemented PBs at the time of the interviews³¹. DPs are thus the only option available for users in LA#2 that do not want to take LA-managed care. Upon assessment, prospective DP users in LA#2 have their hours of care converted into a cash payment at a lower hourly rate compared to LA-managed care. DP users can choose to have their DPs managed by one of four home care agencies under a scheme denominated Independent Service Fund (ISF). The ISF is aimed at diminishing the burden of managing DPs directly (e.g. payroll management), while allowing users greater flexibility in defining their care plan with the agency managing their DP. Under the ISF, DPs are paid directly by LA#2 to the home care agencies, which also allows for greater control over their use. In both LA#2 and LA#3, LA staff interviewed recognised that older DP users faced less constraints in changing home care agencies than users on LA-managed care. The former could freely change agency at any time, while the latter often faced a lengthy waiting time to change agency or needed to have a reasonable motive for the change to take effect.

The monitoring of how DPs are used is carried out by the brokerage team in LA#3 after the first three months and on a yearly basis after that. In practice, LA#3 staff showed more concerns about how users spend the PBs that had been taken as DPs. Monitoring of DP use is arguably stricter than for the other two LAs. DP users in LA#3 cannot accumulate unspent DPs, (e.g. to account for contingencies), unless specifically authorised by the LA - otherwise, the unspent DPs have to be returned. The above described LA-held bank account and pre-paid card was aimed at facilitating and speeding up the process of opening a dedicated bank account required for DP users, but, as openly admitted by LA#3 staff, it was also meant to allow for tighter control over the use of DPs. Not only did it prevent cash from being used to pay for items other than care transactions, but the LA could instantly check on amounts spent or left unspent as it also has live access to the bank account. LA#2 also has similar

³¹ According to LA staff interviewed, LA#2 planned to introduce PBs by April 2013.

limitations in place regarding the accumulation of DPs. The exception is the ISF, which allows users the possibility to accumulate up to 3 months of unspent payments for contingency. Among the participating LAs, LA#1 was the one whose staff members were arguably more positive about the option to take PBs as a DP. Partially as a consequence, LA#1 follows a purposely “hands-off” approach to monitoring the use of DPs. There is a yearly audit on how the money is spent, but otherwise there are no directives favouring either agencies or professional PAs as the deployment option of DPs.

At the time of the interviews, all three LAs had set their eligibility criteria to substantial and critical needs level after having initially provided publicly-funded care also to users with needs assessed as moderate. Four years before the interviews took place, LA#2 had further tightened eligibility by dividing the substantial level in two echelons, lower and upper, and providing publicly-funded support to the latter only. Staff of all participating LAs recognised that as eligibility thresholds tightened, users receiving publicly-funded care were becoming frailer. Concomitantly, as budgets diminished, personal care is prioritised in publicly-funded care and other needs such as socializing are now much less often considered for funding. Concerns regarding how users spend public money also underlined some of the interviews from staff. Reflecting national regulations that normally prevent the employment of close co-residing relatives, the use of DPs to employ relatives as PAs is approached with caution and decided on an individual basis in all three participating LAs.

6.2 THE SAMPLE OF OLDER USERS OF DPs

A total of twenty-four in-depth interviews were carried out in the three LAs. The summary characteristics of interviewed DP users are displayed in Table 6.2. While LA#2 and LA#3 were well represented among interviewees, there was only one DP user interviewed in LA#1. This reflects the different strategies followed to contact potential interviewees: directly, or by telephone by staff in LA#2 and LA#3, and by posted invitation package in LA#1 (see section 5.1.4).

Table 6.2 – Characteristics of the sample of older DP users – number of interviewees by Local Authority

	LA#1	LA#2	LA#3	Total (%)
Gender				
Male	0	4	2	6 (25%)
Female	1	6	11	18 (75%)
Age				
60-69 years	0	4	2	6 (25%)
70-79 years	1	4	2	7 (29.2%)
80-89 years	0	2	6	8 (33.3%)
90 years or older	0	0	3	3 (12.5%)
User typology				
Purchaser	0	3	8	11 (45.8%)
Employer	1	4	1	6 (25%)
Relational	0	3	4	7 (29.2%)
Health condition				
Physical impairments	0	7	4	11 (45.8%)
Mild dementia	1	0	2	3 (12.5%)
Dementia	0	0	6	6 (25%)
Other	0	3	1	4 (16.7%)
Interviewed user				
Self	0	6	3	9 (37.5%)
Self with spouse	0	3	1	4 (16.7%)
Proxy with user present	1	1	7	9 (37.5%)
Proxy with absent user	0	0	2	2 (8.3%)
Living arrangements				
Alone	0	4	4	8 (33.3%)
With spouse	0	4	2	6 (25%)
With children	1	0	5	6 (25%)
With other relatives or people	0	2	2	4 (16.7%)

Notes: Data at the date of interview (March – May 2013).

Mild dementia refers to users that were not confined to bed and/or still able to take part in the interviews.

Regarding the age distribution, almost half of the interviewees were 80 or older at the time of the interview and all were quite frail. The majority of interviewees were also women. Among the interviewees, two health conditions are the most prevalent: physical impairments, linked to conditions such as stroke or diabetes, and dementia. Among the conditions reported under “other” are multiple sclerosis, AIDS and Addison’s disease. The age and health profile, i.e. high prevalence of dementia, reflects the higher eligibility thresholds to access publicly-funded care in the three LAs studied. The sample, as is mostly the case for qualitative research, is not meant to be representative of the older population or of older users of DPs in a probabilistic

manner (Ritchie et al, 2003). However the gender, age and health profile provide an indication that the sample represents a relatively varied profile of DP users rather than a more extreme one.

Living alone is the mode living arrangement among the users in the sample, while a quarter of interviewees were co-residing with their spouse at the time of the interview. In addition one in four interviewees was living with their children and the remaining were living with other relatives or acquaintances. Purchaser-type users formed the largest group of DP users interviewed, followed by the relational users and the employer users. Proxy interviewees were mainly associated with DP users with dementia, while all those people with physical impairments were able to speak for themselves.

Another way to observe the sample is provided in Table 6.3, which depicts the same characteristics of users as above by user typology rather than by LA. Despite being a relatively small sample and being purposely sampled, this information is arguably of interest to analyse if any of the typologies had a particularly different socio-demographic pattern that could be linked to the answers. Women were predominant in all the typologies and there was not a clear correspondence between any of the user typologies and health conditions. For example, among people with dementia, there were purchaser, employer and relational-type users. The employer-type users were slightly younger than the other two profiles, which could hint that they had better conditions to manage employment relationships with their own PAs. As for living arrangements, purchaser and relational users had a higher share of individuals living alone. From the relational group, only three interviewees had employed relatives as their PA, which must be understood in light of the restrictions placed on the use of DPs to hire close co-residing relatives (see section 6.1). All three cases referred to DP users with dementia; in two of them they were co-residing with their paid (family) carers.

Table 6.3 – Characteristics of the sample of older DP users – number of interviewees by typology

	Purchaser	Employer	Relational	Total (%)
Gender				
Male	3	2	1	6 (25%)
Female	8	4	6	18 (75%)
Age				
60-69 years	1	3	2	6 (25%)
70-79 years	3	2	2	7 (29.2%)
80-89 years	5	1	2	8 (33.3%)
90 years or older	2	0	1	3 (12.5%)
Health condition				
Physical impairments	5	2	4	11 (45.8%)
Mild dementia	1	1	1	3 (12.5%)
Dementia	3	1	2	6 (25%)
Other	2	2	0	4 (16.7%)
Interviewed user				
Self	4	2	3	9 (37.5%)
Self with spouse	1	2	1	4 (16.7%)
Proxy with user present	5	2	2	9 (37.5%)
Proxy with absent user	1	0	1	2 (8.3%)
Living arrangements				
Alone	4	1	3	8 (33.3%)
With spouse	2	3	1	6 (25%)
With children	2	1	3	6 (25%)
With other relatives or people	3	1	0	4 (16.7%)

Notes: Data at the date of interview (March – May 2013).

Mild dementia refers to users that were not confined to bed and/or still able to take part in the interviews.

The descriptive statistics presented in Tables 6.2 and 6.3 show that the sample is relatively diversified in its socio-demographic characteristics, also in terms of the three types of users around which the sample was defined.

Finally, in the course of the interviews it emerged that the majority of DP users had had previous contact with care provided by home care agencies before. Only 4 of the 24 interviewees had no previous experience with care before taking up DPs. Of the remaining 20 interviewed users, 19 had previously received LA-managed care for periods ranging from 6

weeks to several months³² and one had previously received privately paid care for a couple of years.

6.3 USERS' INITIAL CHOICE

In this first section on the actual findings arising from the interviews with users of DPs, the focus is on the initial decision of whether to purchase care from a home care agency or to hire a PA. The focus is also on the decision regarding which particular agency or PA to choose. This first section thus analyses the role played by the relational aspects of care in the initial decision about which deployment option of the DP to choose. This pertains to the first hypothesis under investigation – whether the value assigned to the relational aspect of care was reflected in the choices made by the user. One of the issues related to the relational aspects of care, covered in this section, is whether users preferred to hire acquaintances so as to avoid uncertainty around the identity of the paid carer.

This section begins by depicting the context leading to the take-up of the DP, namely the user's previous experiences with care. This is potentially salient to the hypotheses under study, as it may reveal something about the preferences of users, or circumstances that limited their choice. Subsequently, the narratives of interviewees are analysed around the initial choices made and to what extent the choice *from whom* to receive care impacted that decision. Finally, the search process leading up to the choice of a particular PA or agency is depicted in the third section. This is of relevance to the research as it refers to how users overcame the experience good nature of care when searching.

6.3.1 CONTEXT LEADING TO THE DECISION TO TAKE UP DPS

Overall sample

The interviewed users reported a number of different circumstances that surrounded their decision to take up DPs. These circumstances can be grouped into two broad categories. The first refers to contexts of deteriorating health conditions, or the collapse of existing care arrangements leading to a potential unmet need for care. These examples are in line with Glendinning's (2008) reference to making decisions about whether to take DPs in a context of duress. The second category refers to dissatisfaction with care provided under the previous

³² LA-managed care refers only to home care in this context and not community care such as day care centres.

care arrangement, mostly by agencies providing LA-managed care. The latter was perhaps the strongest narrative, as most users had some contact with LA-managed care before being offered or requesting DPs. Each of these categories is analysed in turn.

Many interviewed users described situations beyond their control that had triggered the option or offer of DPs during a time of duress. Among these were deteriorating health conditions. Often, their health had suddenly deteriorated after an acute health episode such as a fall or surgery, but there were also cases of slow but continuous health decline that eventually reached tipping point (e.g. deterioration of symptoms related with dementia). Apart from changes in their health condition, users also often came into contact with DPs after their existing care arrangement had changed due to circumstances beyond their control. This included the deterioration of the health condition of the family carer that was also the main carer, the inability of the family carer to continue caring due to changing life circumstances (e.g. because the family carer moved to a different location), or exhaustion by the main family carer. Changes in the care arrangement could also involve professional carers, such as those employed by agencies, following dismissal or the ending of the contract between the LA and home care agency.

In these contexts, interviewed users referred to the impact that the sudden changes had on their state of mind at the time when many of them first came into contact with DPs. Feelings of anxiety were often mixed with pain while users tried to adapt to their new circumstances: *“I’ve suffered a lot with anxiety and that sort of thing, it was very bad originally after I had the accident, it just knocked my confidence off everything”* [LA#3 011, male, purchaser, aged 66].

The other broad reason for taking DPs was linked to dissatisfaction with the care provided until that point. All the complaints were directed to LA-managed care provided by home care agencies, except in one case where it referred to privately paid care also provided by a home care agency. The complaints focused on two main aspects: agency carers and timing.

Regarding agency carers, the complaints centred on lack of continuity and their disrespectful or inappropriate conduct. A frequently voiced complaint was that agency carers would often change because of high staff turnover in agencies. This meant that users were not able to build a relationship with agency carers. This was referred to by interviewees from all user types – and new carers sent by the agencies would not be familiarised with the user’s preferences or care needs. They also reported impolite behaviour and refusal to do tasks that were outside the care plan. However more often complaints referred to “uncaring” agency

carers or lack of interaction with users; the latter a typical complaint among relatives of users with dementia:

The carers that were coming in were awful, they didn't speak to mum. The ones that were coming in, they need to come in and say, "Hello [name omitted due to confidentiality], how are you?" And make... they wouldn't get much response but they might get a smile. [LA#3 010, female, purchaser, aged 87, proxy with user]

Complaints with timing revolved around issues of reliability, or rather lack of it – agency carers that were late or simply failed to show up – and around what was felt like *time-trial* care with agency carers rushing to deliver care and/or providing less hours than they were supposed to:

And we put up with it for a long time, even when, you know, they were not on time or they wouldn't come, you see. And they wouldn't phone up and say that they were going to be late or whatever. [LA#3 002, female, purchaser, aged 80, proxy with user]

The users were often understanding of the reasons which led agency carers to be late, such as lack of own means of transportation, or carers being overworked by agencies, but this still caused palpable dissatisfaction.

What was common to most discourses around dissatisfaction with care was also that users felt the inability or unwillingness of agencies or LAs to bring about change, i.e. to act on the causes of dissatisfaction and to improve the service. The complaints about the *revolving door* of agency carers, the tardiness of care or inappropriate care, were accompanied by narratives of repeated and frustrating contacts with the agencies or LA staff. These complaints had been met with replies ranging from sympathetic and apologetic to outright dismissive, but the end result was that users did not see any improvement in the care they received. In some cases, it was clear that users welcomed the DPs, when they eventually came into contact with them, as a way to “opt-out” of their current care arrangement or to limit their contact with what they perceived as unresponsive LA-managed care.

Changes in the health condition or caring arrangement and narratives of dissatisfaction with care were not mutually exclusive. Often the sudden deterioration of the health condition heightened the complaints or the unsustainability of care provided by agencies.

While changes in health or caring circumstances could be sudden and trigger irreversible changes in the life circumstances of users, the dissatisfaction with care provided under LA-managed care was of a more continuous nature. In light of this, one issue probed during the interviews was whether users who did not experience a sudden change in health or caring conditions had more time to gather information about DPs and eventually think about how best to use them. Users that had been dissatisfied with care for a longer period of time did not seek to gather information about DPs more actively, according to their own accounts, nor did they take more time to consider their options. The views of interviewees regarding this matter are well exemplified by the following narrative:

Until you are in that situation you are not going to know. Really, if someone had told me about five years ago I would have said "Why are you telling me? It's got no relevance to me." You only start looking into that once you are in that situation. [LA#2 004, female, purchaser, aged 77, proxy with user].

The users that had previous knowledge about the existence of DPs or a deeper understanding of their workings had acquired this information mostly by chance in previous contexts of their lives, for example, through previous employment in a nursing home or by being the representative of the users of a day care centre. These users had later demonstrated a better knowledge of the workings of the DP (e.g. how to spend and manage the DP) and had been able to use this to their advantage, as it will become apparent in latter sections. To borrow from an expression applied to health care, they were "expert users" (Greener 2007). Only one family said that they had gotten hold of information on DPs on their first contact with social services and then used this information much later when their older relative's savings were exhausted and they re-applied for publicly funded care. They provided a rare example of having had more time to think about their options.

One arguable advantage that users with a long track record of complaints had, was that they might have had more concrete ideas about what they wanted to address with DPs, i.e. more time to form their preferences, be it continuity of carers or timely care.

The circumstances surrounding the first contact with DPs seem to suggest that interviewees with previous experience of LA-managed care were somewhat unsatisfied with the inability to develop some connection with their agency carers – i.e. lack of continuity – which provides already some clues as to the significance of the relational aspects of care that are salient to the first hypothesis under study. Possible differences in this respect between groups of users are explored next.

Differences and similarities between different groups

On the surface at least, the narratives of purchaser users showed them to be as critical of care previously provided by agencies – in the context of LA-managed care – as the other users who had previously received such care. The main complaint of purchasers, however, was linked to unreliability, i.e. with carers from agencies showing up late or not showing up at all to provide the care they required. Complaints regarding continuity were rarely present in the narratives of purchasers regarding the care previously provided from home care agencies. This is in contrast with the relational and employer users' narratives. These users often referred to the lack of continuity of agency carers and their inability to establish a rapport as their main criticism of the care provided by agencies. These issues featured particularly high on the list of complaints of relatives of users with dementia (albeit not exclusively and not among all relatives of people with dementia). Purchasers seemed to have attached less weight or to have been less critical of the relational aspects of care provided by agencies.

For employers, it was clear that one important issue had been the experience of significant constraints in accessing care services that met their needs, i.e. to find agencies willing or able to carry out the tasks they required. This was one issue that was not so apparent when analysing the narratives of the sample as a whole – as seen above – but that featured clearly among employers when comparatively analysing the narratives of the different types of users. The following transcript illustrates one example of this, as the interviewee expressed difficulties in finding agency carers qualified to handle a particular condition:

The agency then sends a set of lines on how wonderful their staff is! Competency this and that and HIV trained. They can probably do brain surgery and maternity care in the desert! Who says so? Where is the evidence? No checks! [LA#2 007, male, employer, aged 64]

The comparative analysis of the narratives of different types of users seems to indicate differences regarding what each had found as particularly lacking in LA-managed care that relates to the research question of this study. In this respect, it seems that purchasers valued less the relational aspects of care than the employer and relational users. At the same time, employers seemed to have previously had greater difficulty in accessing suitable care. What follows is a more detailed analysis of the initial choice of home care agency or PA made by the interviewees.

6.3.2 FACTORS IMPACTING THE CHOICE OF EMPLOYING ACQUAINTANCES, STRANGERS OR PURCHASING CARE FROM AGENCIES

Overall sample

When provided with the DPs, there were a range of factors driving the deployment decision as expressed by older DP users or their proxies in their narratives. One of the points of interest for this study was to explore whether relationships had been an important factor driving the initial choices, for example, to what extent users had favoured acquaintances to overcome uncertainty over the identity of users.

A significant minority of interviewees already had someone in mind as a potential PA when taking up the DPs and this shaped their initial choice. Other factors that impacted initial choice were: seeking to have control over the identity of the paid carer and ensuring the continuity of care received, i.e. that the same person would be coming to their home. There were, however, other factors impacting the initial choice that did not seem related to the relational aspects of care. Among these were: wanting greater control over the tasks and timing of care; guaranteeing appropriate backup in case the paid carer was sick or on holiday; and, finally, many interviewees referred to administrative burden as one of the factors driving their choice. These factors were often complementary in the narratives of interviewed users; each is analysed in turn.

While the identity of the paid carer was recognised as being important for the majority of users, for many this was indeed the main reason driving their choices. This was clear for those that had sought to employ someone they already knew, which included not only relatives or friends, but also former agency carers. In at least one case, the user and her spouse had found a carer from an agency whom they liked. When confronted with a possible change of carer after the home care agency had lost its contract with the LA, they had opted for the DP to keep the carer as a PA. In another case, the user complained that he was unable to choose the identity of the carer with LA-managed care. The DP was suggested to him by the social worker as a way of choosing his paid carer. This user then proceeded to hire a relative of a former agency carer whom he already knew as his PA.

The impact of the relational aspect of care was also evident among interviewees that wanted greater control over who would be their paid carer. This was particularly important for families of users with dementia, as they considered the ability of their relatives to accept care, particularly personal care, or to feel “at home”, was very much determined by the empathy

established (or not) between the paid carer and the user (see section 6.6). The identity of the paid carer also featured prominently in two narratives where interviewees clearly sought not just a carer but also a “companion”. Both interviewees to whom this applied were living alone, but at the same time had regular visits from relatives.

One of the salient complaints about previous home care agencies had been the high staff turnover (see section 6.3.1) - thus ensuring continuity ranked high on the preferences of many interviewed users. Having control over the choice of from whom care was received was thus often associated with ensuring continuity of care. For a subgroup of users – those with dementia or their proxy respondents – continuity was deemed central to ensure that provision of care would be accepted by the users as they came to establish a closer rapport with their paid carers. For others, continuity ensured that one could establish a rapport with the paid carer and that he or she knew how to provide care according to the user’s preferences and was knowledgeable of the user’s needs. Continuity could thus also be linked to the definition of tasks:

And if you've got two carers through DPs, again, I'm talking through what I've been told, there is no continuity. Once one carer has done something, how does the next one that is coming in know what has happened if there is nothing written down? [LA#2 003, female, employer, aged 60].

For many of the users, however, the choice of *from whom* to receive care had also been perceived as a source of anxiety. In order to have control over the identity of the paid carer through direct employment of PAs, users had to overcome initial deeply-rooted uncertainties about their trustworthiness. In these cases, users had to trade off anxiety in order to have more control over the identity of the paid carer. Many felt uncomfortable with bringing a stranger into their own home or “taking someone off the streets” as one of the interviewees put it:

I think I would just find it hard if I just had to advertise for somebody and take him off the street, you know, because there are no other people in the house. It's just me. Occasionally my son is here. But that's occasionally when the carers are in. If I'm upstairs, you don't know what they are doing downstairs, or vice-versa. [LA#2 003, female, employer, aged 60].

When probed about the possibility to employ acquaintances as their PAs – as a way to address the anxiety in employing a stranger – many of the interviewed users expressed

concerns about not wanting to mix relationships, i.e. the friendship or kinship and the caring relationship. This preference hints at the possible role played by societal values in shaping people's decisions (England & Folbre 2003), for example, regarding responsibility for caring for frail older relatives. It is a topic whose complexity merits a more detailed account of the interviewees' answers and will be revisited in greater detail later (section 6.4).

The choice of whether to employ a PA or purchase agency care was also often linked to the definition of tasks and times – both the duration and schedules. For a number of interviewees, their choice of whether to purchase care from an agency or hire a PA was driven by the perceived added flexibility that one or the other option offered. When probed on what this added flexibility meant exactly, users referred to the ability to better tailor tasks to their needs, or having the PA doing “*things which are perhaps not entirely in her remit*” [LA#2 008, female, relational, aged 75]. This included tasks that agencies had previously not been able or willing to carry out. One needs to remember that many of the interviewees came to DPs after consistently not being able to get the care they wanted from home care agencies under LA-managed care. This included domestic chores such as cleaning the house or other tasks such as shopping or dropping correspondence at the post office.

Flexibility could also mean more control over time. Many users reported having made their choice according to what they thought would allow them greater leeway in defining timings and schedules, often in the face of changing needs or conditions that did not lend themselves to fixed schedules. Often greater flexibility was equated with the possibility to hire PAs. On the flip side of this argument, one proxy interviewee made her choice (in her case for an agency) precisely because her mother's condition required her to take medication at fixed times and flexibility in terms of time was entirely the opposite of what she was looking for. Few of the other interviewed users had, however, such conditions that required (or allowed for, depending on the perspective) on the whole a fixed schedule of care. Greater control over time could also mean getting paid carers to stay longer than their allocated time, which many perceived as being easier to get with employed PAs.

Once provided with DPs, another issue that featured prominently in the majority of narratives was the issue of reliability and having a *backup*, as seen before. Many of the interviewed users had come into contact with DPs after their experience with unreliable home care agencies. One might assume that this might have left a deeply negative impression of the workings of home care agencies and that these users would be unwilling to resort to agencies again. However negative their past experiences were, users mentioned how they had to balance these against the other alternatives (e.g. employing a PA or an acquaintance)

and the possibility that the latter would also let them down. Choices could thus be made on the basis of which option was deemed more able to either provide trained and competent paid carers, or more importantly, able to secure an adequate replacement for when the paid carer went on holidays or was sick. The following excerpts from interviewees who had opted for an agency illustrate this point:

You wouldn't have the backup with a neighbour would you? The neighbours here all need a holiday. Who is going then to look after you? [LA#2 001, male, purchaser, aged 71]

Because you're looking at other people's lives now and whether they have young children or what sort of age group they're in, whether they are available to you or whether they've got to go off and pick up their children from school and that sort of thing, you see. So you're straddled with that and tied with it. But if you're with an agency that is their problem, you know, because you're paying for it, that's what you're paying for. [LA#3 002, female, purchaser, aged 80, proxy with user]

Finally, another factor that DP users weighed in their choices was the administrative tasks that came with the decision to employ a PA. Even if the LAs had established mechanisms to help users deal with these, namely by contracting the services of payroll agencies and other support agencies (see section 6.1), these could still be seen as relatively daunting tasks. This is exemplified in the following excerpt from a user that referred to this as one of the reasons for opting for a home care agency:

Yeah, 'cause they know they're going to be able to handle the paperwork. Like now we are getting too old to do this sort of thing, you know. Really, I am. I was never an office worker and I could see straight away the problems that may arise with insurance and holidays and bookings and all that. You'd be on your own. [LA#3 002, female, purchaser, aged 80, proxy with user]

When weighing in their initial choices, users referred to a number of factors that included some which directly pertained to the choice of the paid carer – the first hypothesis being explored in this study – and to the definition of tasks – the second hypothesis. There were also, however, other factors present that show other concerns such as securing adequate backup. Whether these factors featured differently among the groups considered in this study is analysed next.

Differences and similarities between different groups

The above factors leading to the decision to rely on a home care agency or PA (previously known or not to the user) weighed differently in the decisions of users from each of the three typologies. There were, in this respect, clear differences between the groups.

The issues that dominated the narratives of purchaser users were concerns with reliability (e.g. showing up on time) and having backup in the case of holidays or sickness of the paid carer. It was clear that they valued receiving reliable care services and that this had impacted their decision on how to use the DPs. Despite having had previously dissatisfying experiences with the care provided by agencies, this type of user still regarded agencies as a more reliable option than relatives or neighbours:

And I've even thought maybe I should have a carer in here and that could be a wage for somebody. But if that carer got sick and I never had a backup then it would drain me. [LA#3 004, female, purchaser, aged 74, proxy with user]

A related argument often expressed was also concern that the whole process of employing a PA and dealing with the mandatory insurance and tax responsibilities would prove too daunting (e.g. see quote by 'LA#3 002, female, purchaser, aged 80, proxy with user' on the previous page).

In the narratives of purchaser users, issues around the choice of from whom to receive care or related issues such as continuity – i.e. having the same person coming to their house – were seldom mentioned as driving forces behind their decision to rely on agencies rather than PAs. In fact, many said that they were not offered a choice of carer with agencies. Similarly, issues around the tasks to be performed were also very much absent from this group's narratives.

Among the relational interviewees, some were people with advanced stages of dementia and their proxy respondents mentioned that ensuring continuity and the possibility to remain and be cared for in their own homes had been crucial in their decision to become full-time PAs or employ other relatives as PAs. Continuity, and the ability to establish a rapport, were key aspects for this subgroup of relational users (or their proxies):

Yeah, 'cause she wasn't a lover of different people coming in. I mean if it had been with like one person that she'd liked that came in all the time then she probably

would have been all right. [LA#3 003, female, relational, aged 92, proxy with user]

Among the other relational users, i.e. those that had employed PAs that were not their relatives, the ability to choose the paid carer also featured predominantly in their choices even if for different reasons. One of them was also seeking *companionship* from the paid carer, while another wished to maintain the long-tenured agency carer in the face of a change of agencies delivering care in one of the LAs. A third one wished to employ and thus pay her caring neighbour.

As a rule, relational and employer users had adapted to whatever administrative hurdles there might have been and the majority found it relatively straightforward to manage their payments and related insurance and tax-obligations through payroll agencies. One employer interviewee actually made a point of managing the DP himself so that the PA could be paid more money.

As seen before, employer users, as well as some of the relational users, had often experienced significant constraints in accessing care services that met their needs, i.e. to find agencies willing or able to carry out the tasks they required. This continued for some when in DPs as the amounts their DPs entitled them to were often too small and they therefore found it difficult to find agencies willing to accept them as clients:

You know when you can hear at the end of the phone and they are "Well, you know..." and I just couldn't be bothered. You can tell on the spot, you can tell whether they want it or not. I spoke to a couple of carers that worked with agencies, if they could fit me in and... no. [LA#2 003, female, employer, aged 60].

This seems to indicate that budgetary considerations were also partly driving the choices of some of the employer or relational users. This means that the choice to employ a PA could also be driven by economic considerations rather than relational motivations alone. For example, one interviewee who was an "expert user", i.e. someone with a good prior knowledge of how DPs worked, wilfully opted for a PA in order to get more care out of the small hours of care that her DP entitled her to. Employer users had also found it difficult to find qualified paid carers to handle their condition (e.g. HIV) or wished to have control over what care was delivered to them (e.g. deciding when the mother would be given a bath). Hiring a PA, whether previously known or not, was in general perceived as allowing greater flexibility in the definition of tasks (see section 6.5). These could also be seen as examples of

how the DPs – by allowing users to employ PAs – had in fact expanded the choice set of users (Klein & Millar 1995).

Issues surrounding the identity of the paid carer were very much present in the narrative of employers. Similarly to the above-stated example of the relational user, one of the interviewees in this group also clearly sought to have a “companion” as well as someone to provide care. In both cases, having command over the identity of the paid carer had been paramount in the choice of using the DP to employ a PA. Even though employer users had decided to hire a PA rather than opting for a home care agency, they still viewed them as having an advantage in terms of providing backup in case something happened to their PA. There was some anxiety about what would happen if their present PA were to quit and thus leave them searching for another appropriate paid carer:

I felt very anxious to be quite honest. Because, when you're with an agency it's like a safety blanket. You know that if someone is not going to come up for work, you've got backup. The person might come a bit later, but you know that there will be someone there that day, when you're with an agency. So you have that backup cover. [LA#2 003, female, employer, aged 60].

In the narratives of the employer group about the initial choices made, there was also a palpable anxiety about the identity of the paid carer. For example, many referred to having limited initial information on the PAs they employed (see section 6.3.3). For relational users and purchasers, the uncertainty and anxiety over the choice of paid carer was much less present, albeit for different reasons. For the former, the anxiety about the identity of the paid carer had been addressed by employing people already known to them, while the latter had often merely trusted the choices made by home care agencies, in a sort of devolved decision to *professionals*:

And the trust, you know, that they're not going to abuse my mother-in-law [name omitted due to confidentiality]. 'Cause if I'm gone, I'm out, I'm not seeing what's going on. So with an agency they can just send anybody along. But this way I can do the hiring and the firing. [LA#3 006, female, relational, aged 80, proxy without user]

I just sort of thought, oh well if I go with this agency [name omitted due to confidentiality], Peter's pretty accommodating with finding the right sort of people. [LA#3 010, female, purchaser, aged 87, proxy with user].

The option of hiring a relative or acquaintance as a way to circumvent uncertainty was either not available for some employer-type of users or not considered an option. For some, their relatives lived too far away and/or their communities were not closely knit enough that they could rely on neighbours. Others did not want to burden relatives or were wary of mixing employment and kinship relationships. While some employer-type interviewees commented that relatives did not live nearby, which ruled them out as a carer - a situation also referred by a minority of purchasers - it seems that the size of social networks did not have a great impact on the initial choices of interviewees. In fact, when probed further, interviewees living alone or with few or no relatives nearby offered similar reasons for not hiring relatives or acquaintances as the other interviewees with more available social networks. In both cases the reasons were based on issues of power (an issue developed further in section 6.4.3 below) and reliability.

Factors more directly connected with the relational nature of care, such as seeking greater control over the identity of the paid carer or ensuring continuity, were much more present in the decisions of employer and relational-type users. This seems to indicate that these users attached greater weight to the relational aspects of care than purchasers – thus only partially confirming the first hypothesis under study. There were, however, also other reasons driving the initial choices of the employer and relational-type users. These included budgetary constraints and the perceived idea that with PAs care could be better tailored to the needs and preferences of users – somewhat in line with the second hypothesis. The narratives of users also pointed to several trade-offs involved in the initial choices over the DPs, which will be analysed in more depth.

Finally, the analysis of the narratives of different groups of interviewees also sought to systematically explore whether other factors might have been associated or played a role in explaining the initial choices of users, besides the aforementioned social networks (i.e. having relatives or acquaintances living nearby). Chiefly among these factors were place of residency (LA) and age.

Regarding the former, there was no evidence that LA-specific institutional factors were driving the initial decision to hire PAs or purchase care from an agency. Factors analysed included differences in the management of the DP process, in the possibility to hire relatives as PAs, in the availability of home care agencies or in access to information (see section 6.3.3 below). The majority of constraints noted by interviewees of one LA were also present in the narratives of interviewees from the other LAs. For example, LA#1 was the only LA that had set up a directory of PAs, which could in theory contribute to rendering the process of

choosing a PA less uncertain. However, the only (proxy) interviewee from this LA – who had employed a PA – expressed similar anxiety about the process of choosing a PA than other employer-type users in the other LAs. Similarly, the complaints concerning previous LA-managed care, such as lack of continuity and unreliability, were common to all participating LA.

Conversely, age could have had an impact on the initial choices of interviewees. As evident from Table 6.3, purchasers were on average older than the users from the other two groups, in particular employers. There was a remarkable consistency in the narratives of users of different ages across the groups in the typology used (purchaser, employer and relational-type users). However, it is possible that being younger allowed interviewees to, for example, better cope with the administrative tasks that accompanied the decision to hire a PA, rather than paying an agency.

Trade-offs in decision-making

It seems clear from the narratives of interviewees that the initial choice of whether to pay a PA or purchase care from a home care agency involved a number of trade-offs and the different types of users valued these trade-offs differently. The greater leeway over the choice of *from whom* to receive care allowed by hiring a PA, had to be balanced against greater uncertainty over the identity of the paid carer. Agencies were often but not always perceived as at least offering a safer option in this respect, which could be perceived as a sort of devolved decision-making in the presence of greater administrative burden or categorical trade-offs (Beresford & Sloper 2008). Relational users, by definition, had little or no uncertainty about the identity of the paid carer. Employing relatives or acquaintances, however, was not always such a straightforward solution as many users fretted over their reliability or over mixing employment and family relationships (see section 6.4): *“How do you tell your sister to go in the kitchen to fetch you a coffee? God knows, my sister is very cooperative but she... [laughter]”* [LA#2 007, male, employer, aged 64].

Resorting to an agency often involved some degree of devolved decision power, for example, over the identity of the paid carer, and what was perceived as less leeway to receive care that was not included in the care plan, such as domestic chores. At the same time, however, agencies could provide some peace of mind regarding replacement for the paid carer. Conversely, employing a PA was usually perceived as allowing for greater flexibility in defining tasks and arranging times, and sometimes associated with offering “better value for money”.

Many interviewees were able to either reflect on these trade-offs or even offer their views on them during the interviews without being questioned. This suggested that the users were well aware of these trade-offs. Even those that had opted for other solutions were often conscious of the positive and negative implications that the alternatives implied – even those that had no previous experience with PAs or home care agencies. This led interviewed users to express some occasional ambivalence about the choices they had made. At the risk of sounding repetitive, an example of this was users, who after having opted to employ a PA, still felt unsure about what would happen if the paid carer fell ill or left. Recognising the advantages and disadvantages posed by alternative options, one interviewee sought to combine both, by hiring a PA (not known) as the main paid carer for her mother, while at the same time keeping the agency as a fall-back option:

So we decided to go with the agency also because if something happens we have someone to back it up and they can temporarily increase the hours. So, yes, that was the main reason why we didn't get rid of them [the agency]. [LA#1 001, female, employer, aged 72, proxy with user]

The several factors previously identified in the choice process of interviewees thus point to the existence of trade-offs that DP users face in their choices over the deployment of DPs. For some users at least, minimising administrative burden or ensuring proper backup was apparently more important than complete choice over both who would provide care and increased leeway over the definition of care tasks. These users were therefore prepared to delegate choice and control over the identity of the paid carer to the agency.

6.3.3 SEARCH STRATEGIES

Overall sample

As mentioned in Chapter 4, the experience good nature of care encompasses not just the relational components (e.g. the identity of the paid carer and how the relationship will evolve), but also the delivery of tasks (e.g. will care provided match the user's needs and preferences) and quality of care. Whether interviewees had chosen to hire a PA or purchase care from an agency, they still needed to search for and find a particular PA or home care agency – although this issue was not relevant for those that already had someone in mind or that employed an acquaintance.

Interviewees provided several accounts of their search process – which varied between each of the three groups as will become evident latter – and strategies employed to counter

uncertainty. All three participating LAs had established Directories with the contacts of home care agencies that operated in their geographical area, or at least the contacts of agencies that had contracts with the LA and therefore had their quality monitored and certified. These Directories were amply used by interviewees to select the agencies.

A similar formal and structured way of conveying information about PAs was, however, absent, even if some LAs had plans to fill this gap (see section 6.1). For PAs, but also for agencies, other sources of information were therefore used in the search process. Chiefly among these was word of mouth. Interviewees referred to a long list of possible sources of information in this respect. Not surprisingly, social workers were considered among the most trustworthy sources of information and those that asked for and received an opinion from social workers quite often followed this opinion, particularly for home care agencies. Other recommendations ranged from neighbours that were themselves employing a carer, word of mouth from friends or relatives, or user organisations or support agencies that were commissioned by LAs to provide information and support in the whole managing and hiring process. Once a PA had been hired and a trusting relationship established, they also became valued sources of information, particularly to hire a replacement for holidays. The advice of PAs was in general very highly regarded – even if the suggestions included relatives or acquaintances of the PA – and taken in the same way as if given by a family member or friend:

I wouldn't know where to go. Unless my carer [name omitted due to confidentiality] could recommend me someone. It's possible she would recommend someone. That would be different. [LA#2 009, female, employer, aged 60, proxy with user]

Other forms of gathering information, such as conducting interviews, were seldom mentioned, even by proxies who were younger and probably more able to handle the process of interviewing prospective paid carers. It was clear that the process of searching was still hampered by lack of certified sources of information and that there were still many grey areas in the market in this respect. This was how a user described the process of searching for a PA:

Well, well. Because what you do is you put yourself on the streets. Where did you find these people? Well, you have a look at windows, you look in newspapers, you ring people up. [LA#2 007, male, employer, aged 64]

In view of the limited sources of information available, interviewees were probed about using *trial and error* in making their choice of agency or PA. Very few mentioned trying different agencies or PAs to see which provided the best match for them. The majority of interviewees' choices – regardless of their type – reflected some degree of prior knowledge of the agency or person in question. Relatives and prior acquaintances employed as PAs are an obvious example. Other interviewees chose PAs who had previously cared for neighbours. Some others had had a chance to “shadow” potential PAs in their caring activities with other people, for example, carers from a day care centre where one of the interviewees regularly went and where she observed their interaction with other users, or carers from the service housing where another interviewee resided. Similarly, among agencies chosen by some interviewees were those for which they had previously worked; or whose manager they already knew; or agencies used by other relatives. There was an clear strong preference for providers (agencies or PAs) on which users already had some information, which is compatible with the uncertainties accompanying the experience good nature of care.

Differences and similarities between different groups

When choosing agencies, purchaser-type users had arguably had access to more formal sources of information about the agency: either LA staff or LA's Directories of agencies, both of which were thoroughly used. Other sources of information such as word of mouth from acquaintances or social workers, where available, were also considered, but purchasers clearly benefited from a more grounded search process as far as the search for home care agencies was concerned. As for the identity of the agency carer, on the one hand, purchasers were seldom given the choice to choose the carer (although they could state some preferences regarding gender, ethnicity or religious background) and thus one could argue that they had less information in that respect. On the other hand, as part of the process of devolved decision-making, home care agencies were often perceived by purchasers as offering a safer option as to the trustworthiness of their paid carers: *“I just sort of thought, oh well if I go with this agency [name omitted due to confidentiality], [name of home care agency manager omitted due to confidentiality] is pretty accommodating with finding the right sort of people”* [LA#3 010, female, purchaser, aged 87, proxy with user]. For relational users, the anxiety was greatly diminished or absent because of their prior knowledge of the person delivering care – usually family members or previous agency carers with whom they had developed a satisfying long-standing relationship.

The anxiety and uncertainty surrounding the choice of paid carer was palpably greater among employer users interviewed in the three LAs. They did not have the advantage of prior

knowledge of the person caring for them that relational users had, and lacked the institutional sources of information of purchasers, as only LA#1 had a directory of PAs in place. Their sources of information ranged from ads in newspapers or local shops – see previous quote from interviewee ‘LA#2 007, male, employer, aged 64’ – to using the internet. For employer-type users in particular, recommendations became a valuable source of information when choosing their PAs. These included acquaintances or relatives who knew potential PAs, or had themselves employed a PA. As mentioned before, among the trusted sources of information were PAs themselves once a rapport had been established. More than using interviews or trial and error, employer-type users chose their PAs following recommendations or word of mouth.

Again, these differences between the several types of users did not seem to reflect dissimilarities between LAs. As mentioned before, only LA#1 had a directory of PAs in place, but the only interviewee from this LA had been unaware of its existence at the time of the initial choice and as no other interviews were carried out in LA#1, the impact of this more structured source of information could not be further tested. Proxies could arguably have been more able to manage the search process, since they were younger and in better health, or use other sources of information (e.g. internet). Despite the age and cohort differences, anxiety and uncertainty were also present in the narratives of proxies.

6.3.4 SUMMARY OF THE MAIN ISSUES RELATED TO THE PROCESS OF CHOOSING AGENCIES AND PAS

This section analysed the context leading up to the initial choice of deployment of DPs, and the role that relationships played in the initial choices made by users. The key findings are:

- The majority of interviewees had previously had unsatisfactory experiences with care provided by agencies in the context of LA-managed care. Most complaints revolved around the lack of continuity of agency carers and unreliable delivery of care (e.g. tardiness). Having a prior unsatisfying experience did not, however, preclude DP users from considering and opting to purchase care from an agency.
- Among the factors impacting the initial choices of DP users were: having already someone in mind to be employed as a PA, seeking to have control over the identity of the paid carer, having greater control over care tasks and their timing, ensuring backup in case the paid carer was unavailable, and lastly the administrative burden associated with each option of deployment of DPs.

- Those purchasing care from home care agencies appeared to be more concerned with getting reliable care and having to shoulder less administrative burden, than the relational aspects of care or defining when, how and what care to receive. They seemed to have opted for a “safer” choice, i.e. with more backup guarantees and also arguably with access to more structured information over agencies, while giving up on perceived flexibility and agency by devolving decision-making over the identity of the carer to agencies.
- Factors pertaining to the relational nature of care were much more central to the initial choices of the users that had employed PAs. These included choosing a paid carer with whom they had had a previous good relationship, or having command over the identity of the paid carer in order to establish a rapport – particularly important for proxy interviewees of users with dementia. While relational aspects were key, some choices also revealed a more economic-type of reasoning, for example, seeking to optimise the amount of care received by employing PAs.
- In opting for a PA, some users were also seeking to get more tailored tasks and more control over time, which they perceived to be associated with employing a PA – a factor that was linked to the second hypothesis under study. For some interviewees, PAs were perceived as allowing them to receive care that the market (i.e. home care agencies) had otherwise not been willing or able to provide.
- The choices made also involved trade-offs. The advantages of employing a PA had to be weighed against costs such as added workload in managing payments and insurance. Other costs could be termed as psychological costs, for example, increased anxiety arising from the limited information over the identity of PAs that were strangers. Employer-type users clearly revealed more anxiety in the process of choosing than the other interviewees. Purchasers seemed to have valued these costs highly (e.g. administrative burden) in their decision to opt for agencies.
- As mentioned in the description of the typology of users (see section 5.1.2), purchaser and employer-type users were deemed to overlap in their lack of knowledge of who their paid carer was; while employer and relational were deemed to overlap as to the ability to choose their paid carer. The findings identified another overlap: purchasers were closer to the relational-type users in expressing less anxiety in the initial choice – despite purchasers and employers not knowing the identity of their carers beforehand. The process through which this worked, however, was differentiated between relational and purchaser-type users: the former had prior knowledge of their paid carers; while the latter experienced less anxiety because they trusted the agency to choose the carer (devolved decision).

To summarise the findings of this section, in view of the research question and hypotheses being explored in this study, it seems that the relational aspects of care played a role in the initial choices of interviewees, albeit not for all groups. Those that chose to employ PAs attached greater importance to factors directly related to the relational aspects of care. Those purchasing care from agencies valued instead factors such as reliability and having a backup. Employing PAs had also been perceived as allowing greater leeway in the definition of tasks, in line with the second hypothesis under study. The flip side of this was that those hiring strangers as PAs clearly expressed greater anxiety and difficulties in accessing information about the identity of the paid carer. Even though purchaser-type users had significantly less leeway in the choice of (agency) carers, they expressed less anxiety over the choice process. They apparently trusted agencies to choose adequate carers. In this respect, purchasers were more similar to relational-type users in showing less anxiety regarding the choice process, albeit for different reasons (relational-type users already knew their paid carers).

When describing their search process, users often mentioned how they had relied on the opinion of PAs with whom they had established a trusting relationship after some time spent together. On the one hand, this further testifies to the importance of establishing relationships in the context of caring. On the other hand, this questions the meaning of the relational aspects of care as applying solely to the issue of employing a previously known person as a paid carer. In other words, the relational aspects of care encompass also the establishment of relationships with paid carers that were previously not acquaintances, i.e. to develop relationships over time. This is a key focus of the next section.

6.4 THE RELATIONAL ASPECTS OF CARE

The previous section showed how relationships might have impacted the initial choices made by interviewees regarding the use of DPs. The focus of this section revolves around how users referred to their relationships with their paid carers (whether from agencies or PAs) not at the initial time of making choices but at the time of the interview, i.e. after some time had elapsed. The findings reported in this section thus refer to how the relationships evolved over time, and how users might have sought to establish different relationships from the start. The relationships might also reflect the different possibilities to develop relationships made possible by different arrangements. Furthermore, this section also analyses how relationships impacted the experience or perceived satisfaction of users with the care received. The findings reported in this section thus continue to explore the first hypothesis under investigation – namely the value assigned to the relational aspect of care.

This section is organised as follows. Firstly, it describes how users defined and built their rapport with the person delivering care, and how this impacted their experience with care. Secondly, it addresses the issue of reciprocity in caring relationships that arose from the interviewees' accounts and how this reciprocity took place and shaped the care received. Finally, it also includes the findings pertaining to the *boundaries* in relationships, for example, how relationships were also shaped by moral considerations and values.

6.4.1 BUILDING AND DEFINING RELATIONSHIPS WITH PAID CARERS

Overall sample

The rapport established with the person delivering care was something that most interviewees repeatedly reported as very important to their experience with care. Detailed accounts of the relational aspects of caring and their salience were offered by interviewees, often on their own initiative, while narrating their experiences with care received. But *what* was valued in the relationships, and how did this contribute to the experience of receiving care?

In two cases, relationships mattered because particular users sought more than “just care” from the person delivering care. They also wanted *companionship* and *social connectedness* from the paid carers. In these two narratives, relationships were not just something that facilitated the caring experience, but very much the goal or aim of selecting their own paid carers.

Beyond these two more extreme cases, for many interviewees the relational aspect of care was very much connected with the concept of *home* and seen as a particular feature of *care at home*. In this context, relationships were deemed essential to diminish the anxiety and uncertainty felt when letting a stranger into the house. This was particularly evident for the proxy interviewees of relatives with dementia in different stages, who felt that their relatives were in a particularly vulnerable situation. In these cases, the rapport with the paid carer was synonymous with establishing trust: “*Yeah, that's important because you need to feel comfortable with the person that comes into your home*” [LA#3 010, female, purchaser, aged 87, proxy with user].

Dependency or declining health often meant that users had to come to terms with a new situation that demanded physical as well as psychological adaptations on their part, an adaptation process that could take time. Sudden deterioration of health or prolonged spells of ill-health, often accompanied by pain and social isolation, could leave psychological scars. In

these cases, a long established rapport with the person delivering care could provide important psychological support that users would not find with occasional paid carers. Similarly, losing one's physical independence could be accompanied by a sense of loss of control or loss of self-confidence. This sense of vulnerability associated with needing care is part of the power dynamics underlying the process of receiving care (see Chapter 2) and the relationship with the paid carer could contribute to alleviate the sense of dependency. The following two excerpts illustrate these two points:

I get up and the pain is unbelievable! On a bad day I would sit down and cry my eyes out. [laughter] On a good day, "Get on with it!", "Walk through it!" It's just that she knows your moods as well. Being someone I know and she would be like "Is this one of them?" It's just having someone that's personal as well as caring. Which I didn't find with carers [from the agency] at all [LA#3 001, female, relational, aged 68].

Yeah, mum's comfortable with them [the carers] and, you know, when you're like unwell and you lose your dignity, that's enough without not knowing the person that's coming in. Because they come in, and anything could happen to mum in the night, that has to feel very personal with my mum [LA#3 004, female, purchaser, aged 74, proxy with user].

The relationships could also be associated with continuity and familiarity and for users with dementia or their proxies, this was considered to be fundamental not only to the wellbeing of the user, but also to slow down cognitive decline. One interviewee offered on account of how the lack of continuity and the inability to establish a rapport with ever changing agency carers had impacted her mother's wellbeing:

And my mum, it actually caused more confusion cause she has dementia and she didn't think it was her house, because she was having all these strangers just coming into her living room. She didn't think she had any control. So, she then got confused about where she was and I mentioned... and again, there was no building of a relationship as there were so many individuals coming. (...) because the other thing that was happening was that if food was left for her to eat, because she didn't think it was her home, she didn't think it was her food. The care plan they had just failed! [LA#3 012, female, purchaser, aged 81, proxy without user].

The above examples refer to narratives of how relationships mattered on their own as an outcome of care. There were other cases where relationships were rather associated with what

they helped to accomplish. For people with more advanced stages of dementia, relationships could be fundamental for users to accept or cooperate in the delivery of care (see section 6.6), i.e. relationships aided in the delivery of care. Other users credited relationships with improving the experience of receiving intimate care. Care often involved relying on someone to be able to perform very intimate personal care. Receiving personal care without feeling somehow alienated or uncomfortable was rendered easier or possible only after a rapport had been established with the paid carer:

[Wife]: If a carer would turn and tell you not to get personal with them [User: But you got to!] when they are dealing with your body you have to have a certain amount of comfort from that person.

[User]: Not get personal? She has to be all over your body! [LA#2 010, male, employer, aged 71].

Regarding the intimacy of care, relationships also allowed paid carers to acquire a better knowledge of users' needs, moods and personal histories. This improved the delivery of care by better matching how care was provided with the user's preferences – in relation to the second hypothesis of the study – as clearly illustrated by the quote 'LA#3 001, female, relational, aged 68' from the previous page.

Finally, interviewees recognised that as the relationship evolved and they became more familiar with the paid carer, they were able to have more leeway in the definition of what care to receive or the care schedules (the latter only in the case of PAs). This pertains to the second hypothesis under investigation – that establishing a rapport with the paid carer would allow for greater leeway in the definition of tasks – and will be developed in greater detail in section 6.5 below.

Relationships could thus be valued on different grounds, varying from being viewed as a fundamental outcome of care on its own, to being considered instrumental in aiding the delivery of care. Given the range of meanings attached to relationships, it was perhaps not a surprise that there were many different types of relationships between users and paid carers in the sample.

The feelings attached to the paid carer could in time and after frequent daily contacts and interactions, develop into a close relationship. The paid carers could be described and considered as “part of the family” by some users. For these relationships, it was not unusual for users and paid carers to rely on each other for tasks that went beyond caring, or for

socialising to take place beyond caring times. These relationships involved great trust and elements of reciprocity between paid carer and user. As an example, one user had regular contact with the family of the PA outside the scheduled hours for care and had entrusted the paid carer with a bank card to carry out the shopping for the user (although the user kept track of the transactions online):

He's even out of his own pocket bought food for me, which... he treats me like... I've been out with him and his family in his car and he relies upon my knowledge on certain things to help him. So yeah, he's more like family now [LA#2 005, male, relational, aged 61].

There were other close relationships, defined also as *kin-like* and involving a great deal of reciprocity, but the above case was arguably the most extreme example.

Other interviewees also had close relationships with their paid carers, but these were defined more around friendship or what one interviewee coined “working-friends”. These interviewees trusted their paid carers (e.g. with the keys to the house), valued the relationship highly and were willing to go out of their way to help their paid carers. One interviewee clearly stated that he preferred to handle the paperwork involved with DP himself so that this particular paid carer could receive more money – something he recognised he would probably not do if in the future this particular paid carer was to leave. In these relationships however, there were more clearly defined limits. For example, it was clear that the relationship existed within a context of provision of services, within a specific time and place – the home of the users during the time needed to perform care – and that these relationships, close as they might be, involved power:

It's like friends you know. It wouldn't be friends like go out to eat or something. It's just in between. Once she goes, she goes and that's it [LA#2 009, female, employer, aged 60, proxy with user].

Even with the carers that I've had I'm not 100%, you still keep something back. You still have to let them know that you are their employer not their friend, although you become like friends [LA#2 003, female, employer, aged 60].

For a non-negligible minority, relationships were defined in a much more detached way. In these cases, the relationship was defined more on a professional level with clear boundaries, for example, regarding discussion of personal matters. The relationship evolved around

feelings of friendliness rather than friendship or quasi-kinship and involved much less deeper emotional feelings or concerns with the paid carer. The exchanges with paid carers were not clearly a focal point of the narratives of these users and the accounts of these exchanges were much more sober: "*There are certain things with the carers or a carer that you might not like to personalise, you know. And... but no, she's fine, she's okay*" [LA#3 002, female, purchaser, aged 80, proxy with user], or "*It's quite friendly. Oh, yes, we have our little chats*" [LA#3 005, female, purchaser, aged 85, proxy with user]. In other words, a significant minority of users did not seek to create a family-like relationship with their paid carers, meaning that close relationships were not perceived as better or preferred. For users with a more professional-like relationship, their narratives focused more on the advantages that could arise from establishing a rapport with their paid carers, although at a more detached level. In the context of the hypotheses of this study, particularly the first hypothesis, this seems to indicate that not all users valued the relational aspects of care in the same way.

Besides being valued on different terms (i.e. in itself or as an instrument), relationships could thus be defined on different levels varying from more professional to something closer to kinship. The meaning of relationships could also change over time, as relationships could play a role in the initial choices about care (see section 6.3) and evolve with time.

Differences and similarities between different groups

Regarding the relational aspects of care, there were differences between the three groups, both on how the role of relationships were perceived, and how deep and emotional each characterised the relationship with their paid carers.

Purchasers linked the perceived quality of care they received from agencies with their feelings towards the agency carer, but they clearly valued relationships more for the *instrumental* advantages that could be derived from them. Some users reported that getting along with the agency carer was an important factor in their valuation of the satisfaction with the care received, for example when receiving personal care. These feelings did not arise with every agency carer and were seen as a strong enough motive to ask the agency to change the carer or to change agency altogether in order to stick with a particular carer if he or she had changed employer. Establishing a rapport with the agency carer was thus also seen as important:

When someone's looking after your personal care it's very important that there's... how can one put it? Or look at it a different way, if you go on a blind date and the

girl [laughs], you won't automatically connect with the person that you... you had the blind date with, and that's the same with carers basically. There has to be a connection there or whatever, or not only is it uncomfortable but it's not possible, in my opinion [LA#3 011, male, purchaser, aged 66].

Among proxy respondents of purchasers with dementia, bonding with the agency carer was seen as decisive to handle situations of challenging user behaviour. This hinted at the possibility, also among purchaser-type users (or their proxies), to develop a bond over time with their paid carers, even though theirs was a much more detached rapport than that reported by other users.

To some extent, the importance of knowing and bonding with the agency carer was part of the process of establishing trust or feeling comfortable with a stranger that was coming to the user's house, one that purchasers had not always had a chance to choose themselves: *"Yes. It is something that builds up. You get to talk about their families and their children. And, you know, it's just more relaxing to us"* [LA#3 005, female, purchaser, aged 85, proxy with user].

In line with valuing relationships more for their instrumental value, the relationship of purchasers with their paid carers was clearly more defined on a professional level. The relationship with carers from the agencies was built around feelings of friendliness rather than friendship, or involving deeper emotional feelings or concern for the paid carer. At least two of the purchaser-type of interviewees maintained contact with former agency carers and referred to these contacts in a quite friendly way, but crucially enough these were contacts or relationships that clearly existed outside and were separate from caring. Overall, there was a clear understanding of the boundaries involved as evident in the following depiction offered by a purchaser interviewee: *"Not necessarily a relationship but someone who is professional. Obviously you get to know them over time but not as a friend, just purely as an acquaintance"* [LA#3 011, male, purchaser, aged 66].

One important question is whether these more detached relationships corresponded to the purchasers' original choices or preferences. As seen before (section 6.3), purchasers had apparently given less weight to relational issues in their initial decision of how to deploy their DPs. In their narratives, most purchasers appeared satisfied with their current professional-like relationships:

Some of them [agency carers] are more friendly than others but most of them, in fact all of them have been entirely professional, carried out their duties in a

professional manner, and that's one of the reasons I stay with the agency perhaps
[LA#3 011, male, purchaser, aged 66].

Not only did the users narrate their preference to contain care relationships, i.e. not to let them develop into friendships, but some actually went to some lengths to limit their relationships with agency carers to a professional one. This was done by clearly imposing strict boundaries, for example regarding social interactions (see section 6.4.3 below). Despite this, one should also bear in mind that purchasers had had much less leeway in choosing the identity of their paid carers (see section 6.3.2), which could have precluded the development of closer relationships. This is an issue that will be developed further in section 6.4.2.

Among employer-type interviewees, feelings of *friendliness* were also present, but many developed deep caring relationships with their PAs and viewed them as friends or almost as family, even though they had not previously known them. Overall, the relationships established between employer interviewees and PAs were clearly closer than those of purchaser-type interviewees. This closeness was something that employer-type users clearly valued and was sometimes contrasted with previous experiences they had had with agency carers.

There was extreme trust placed on PAs, exemplified by the fact that PAs were even trusted with providing references for substitute carers in the event of the PA going on holiday or leaving altogether. There were often also feelings of concern with the PA's wellbeing or family problems. There was still, however, a sense that boundaries existed in the relationship (see section 6.4.3). Despite the bond established with the PA, they could not become ordinary friends as this might collide with their employer-employee relationship. This could sometimes create a certain difficulty in dealing with these ambivalent relationships:

There is the problem that some people can be too trusting, you know. Even with the carers that I've had I'm not 100%. You still keep something back. You still have to let them know that you are their employer not their friend, although you become like friends [LA#2 003, female, employer, aged 60].

Employer-type users recognised the advantages that could be derived from establishing a relationship with their PAs. Chiefly among these was the improved experience of receiving personal care and the ability to receive care that better matched their preferences and needs. It was obvious, however, that employers also derived much of their satisfaction with care from the relationship itself, as it allowed them to receive social support and, in at least one

case, companionship. In this sense, not only did these closer relationships seem to be consistent with their original choices, but choosing their PA also enabled employers more control over the development of the relationship:

It's whatever you want it to be, to be quite honest. I think if you are the employer you can have the relationship with your carer how you want to have it. You want to have the distance between the two of you and I will be watching over you? You can do it" [LA#2 003, female, employer, aged 60].

Boundaries were more blurred with the relational-type interviewees, as some among them had relatives as their PAs and acting as their proxy respondents. Proxy respondents of relational users with dementia clearly valued the fact that their relatives were able to be cared for by someone they knew in a homely environment.

[Proxy interviewee]: Well, I mean personally I think it's better. I mean she didn't like the people coming in anyway.

[Interviewer]: Why would you say it's better?

[Proxy interviewee]: Well, I suppose 'cause you're sort of closer aren't you? [LA#3 003, female, relational, aged 92, proxy with user].

Those that had employed previous acquaintances that were not relatives (e.g. neighbours) enjoyed close relationships with their PAs, which often involved exchanges of *gifts* (e.g. paid meals). These interviewees also referred to their PAs as filling a gap in terms of social isolation or psychological support that was important for them to regain confidence. Interactions with paid carers were also valued and referred to by some of the employer-type interviewees who had closer relationships with their PAs and also by at least two of the purchaser-type interviewees. It was nonetheless apparent that the interactions between purchaser-type interviewees and agency carers were more detached in their nature than those that took place between relational-type and even employer-type interviewees and their PAs. The following excerpts illustrate the differences in the interaction with paid carers between a purchaser-type interviewee (first excerpt) and a relational-type one (second excerpt):

I don't have a problem with it, I like meeting different people and because of living on my own I don't see many people on that level so it's somebody to talk to if nothing else. Whether it... it still is on a professional level, obviously, but

something is better than nothing if you know what I mean [LA#3 011, male, purchaser, aged 66].

She [the carer] is making me go about a bit more than the other one did. How shall I put it, she cares in that respect: "Come and do something", "Come and sit here." And she makes me get up and move. Because the other one couldn't care less whether I did it or not. (...)That's on the days that I'm depressed and feeling sorry for myself and she [current carer] takes me out of it, whilst the other wouldn't give a damn! [LA#3 001, female, relational, aged 68].

The analysis of the narratives of interviewees revealed, on the one hand, that relationships were in general valued across the sample of users, but on the other hand it also uncovered important differences regarding the value attached to relationships and how these are defined. For the purpose of this study, it seems therefore that being able to choose one's paid carer, as employer and relational users did, facilitated the development of closer relationships. This was something that clearly contributed to the satisfaction of these users. Purchasers had much looser relationships with agency carers, but they did not express dissatisfaction with this detachment. Quite the reverse, the professionalism of the relationships was often referred to as a positive aspect. Nonetheless, there might have been other contributing factors to explain the observed clustering of relationships of a different nature among purchasers, employers and relational users. Chiefly among these factors were living arrangements and social networks, place of residency (in which LA was the interviewee residing), health condition, age of the interviewee, tenure of the carer and frequency and duration of contacts in the caring relationship. The possible influence of these factors in explaining differences in relationships was therefore systematically explored.

Possible confounding factors behind relationships

Among the first factors to be analysed in conjugation with different caring relationships were living arrangements and social networks. The differences observed between groups of interviewees regarding the relationships established with carers or the valorisation of the relational aspects of care could reflect differences in living arrangements or social networks. For example, having fewer friends or relatives, and limited contact with them, could be associated with closer relationships with paid carers – the latter substituting for the lack of close contact with acquaintances or relatives. Interviewees were therefore probed about their social network, in particular the existence of close relatives and the frequency of contact. The two interviewees who sought to receive companionship besides care (one

employer-type user and one relational-type user) and had developed very close relationships with their paid carers, were both living alone. Despite this, it was not clear that the relationships with their paid carers were replacing closer relationships, as at least one of these interviewees received frequent daily visits from one of his sons who lived close by. Conversely, other interviewees who also lived alone, reported detached rapports with their paid agency carers, and seemed satisfied with the nature of these rapports. There were also interviewees who reported closer relationships with their paid carers and were either co-residing with their spouse or child/ren, maintained active social lives, or both. For example, one relational interviewee who lived alone and reported a close relationship with her paid carer (a former carer from an agency) – they frequently confided to each other about their personal lives – was also active with a local theatre group at least once a week and frequently went to a social club. A couple who had changed to DPs to maintain her previous agency carer also reported frequent social outings. Living arrangements and social networks were therefore apparently not systematically related with differences in the rapport with carers or with differences in the valuation of the relational aspects of care.

Place of residence was also not associated with any particular cluster of relationship with carers (see Table 6.2 for additional information) as different types of rapports with paid carers were found across LAs³³.

Another factor considered was the health condition of respondents, particularly whether those having greater limitations in getting out of their homes or those showing signs of depression valued their relationships with paid carers differently. Having difficulties in mobility – thus being more limited in being able to meet friends or relatives without additional support or help – was not associated with particular relationships with paid carers. Apart from users confined to their beds due to advanced stages of dementia, four interviewees reported having difficulties in getting out of their houses, for example to meet friends. They recounted different views on their rapport with paid carers, ranging from very close to fairly detached relationships.

The analysis also considered whether the reported mental health of interviewees was associated with particular relationships. A number of interviewees with closer relationships with paid carers had also described moments in which they felt disheartened or sad, as exemplified by an earlier account of one interviewee: *“I get up and the pain is unbelievable! On*

³³ The exception was LA#1, where only one interviewee was carried out.

a bad day I would sit down and cry my eyes out." [LA#3 001, female, relational, aged 68]. In these cases the closer relationship with their paid carers helped users manage these moments of sadness. However, at least one interviewee who went out of his way to circumscribe his rapport with the paid (agency) carer also provided accounts of feeling sad and disheartened.

As for the age of the interviewee – another possible proxy for frailty – this was apparently also not systematically connected with particular types of caring relationships. As observed before (see section 6.3 and Table 6.3), employer-type users were on average younger. However, there are examples in the sample of rather different types of relationships with paid carers being described by both relatively younger and older interviewees. Therefore age did not emerge as a possible confounding factor in explaining differences in caring relationships.

It was clear from the narratives of interviewees that time was a necessary condition to develop a rapport with paid carers and indeed references to "time" or "building of a relationship" were often employed by interviewees, even in reference to agency carers. Purchasers had mentioned how they grew to become more familiarised with their paid carers. Time was therefore a necessary condition for relationships to evolve with paid carers. However, unlike employer and relational-type users, it seems that the rapport with paid agency carers did not evolve to become a closer link. Even those purchasers with long-tenured agency carers referred to them in more detached ways as exemplified by the following quote:

[User]: They turn up on time, that's the most important thing.

[Husband]: There is certain things with the carers or a carer what you might not like to personalise, you know. [LA#3 002, female, purchaser, aged 80, proxy with user]

Although time was necessary for the development of relationships, it was not enough to make them family-like.

It was not possible to acquire administrative data on the size of the care packages and therefore on the frequency and duration of the contacts with paid carers. Instead, interviewees themselves provided information on the size of their care packages, although they were not always sure about this information themselves. Some purchasers reported that they received care from more than one agency carer, which could mean that some had

shorter individual contacts with agency carers. These interviewees with multiple agency carers were nonetheless a minority among purchaser-type users and for the most part even these possible shorter individual contacts referred to long-tenured carers. Among the other interviewees, only one employer-type user reported employing two PAs while two relational-type users had more than one relative as their PA. However, it was not clear whether those users that had more than one paid carer actually spent less time with them. For example, most purchasers who had more than one agency carer referred to requiring lengthy individual periods of care, almost every day, i.e. they seemed to have larger care packages.

While analysing the narratives of interviewees on the issue of relationships with their paid carers, one topic did emerge that showed some correlation with the type of caring relationship: the existence of reciprocity and mutual exchanges. This was a topic that had not featured prominently in the literature surveyed (see Chapter 2), which was not linked to characteristics of either carers or users, but rather to the type of relationship. This is the theme of the next section.

6.4.2 RECIPROCITY

Overall sample

Many interviewees had lost some of their functional independence and found themselves relying on the paid carer for basic tasks indispensable to their daily living. This was not, however, always a straightforward one-way relationship with paid carers, or one where exchanges were circumscribed to monetary payments made with DPs. The transcripts contained clear examples of reciprocity that took place at different levels within the caring relationship. Each of these examples is examined in turn.

Arguably the most common form of reciprocity involved the timing of care. Interviewees either adapted their schedule to fit the PA's constraints – arising either from other caring commitments or from the PA's personal life – or established an informal arrangement that provided both PAs and users some degree of flexibility in the timing or duration of tasks. This was an exchange that was clearly based on the notion of *give and take* which went hand in hand with the flexibility (especially regarding timing) that users had previously associated with having DPs:

Absolutely! Absolutely! Very sensible. Yes, I mean, she's wonderful. And it works both ways. If she needs to be somewhere earlier, so she tells me and she goes! I

don't sit there with a stopwatch "Oh, you're 15 minutes due." Not that! No. Adult relationship. And she knows what to do and I respect her and she respects me. Adults. Yeah! [LA#2 007, male, employer, aged 64].

Reciprocity between users and PAs, however, often extended beyond the timing of care and could encompass the exchange of symbolic *gifts*. Included in the *gift exchanges* was the provision of different sorts of moral support to the paid carer. This type of support could range, from merely being an attentive listener to the paid carer, to confiding on his or her personal problems, or supporting a foreign-born paid carer in navigating the English tax and benefit system. On the one hand, this gift exchange, particularly the ability to listen and talk about personal or daily matters, was valued by interviewees as part of the relational aspect of care, i.e. as something that contributed to their perceived quality of care or satisfaction. On the other hand, however, the possibility to reciprocate the care received, even if just by listening to the paid carer's personal problems, also allowed users to regain a sense of independence.

With a carer you need to have something private and confidential. Maybe she will tell you something private about herself. A problem with her boyfriend, or with a friend. When you get a carer after years together and get that quality and they give you good care at the same time, I think you got the package [LA#2 010, male, employer, aged 71].

She comes in and she even puts her in her bed. She puts her up to bed which is great! It's things like that. That's why I rather pay her, cause I know that she is getting her money regularly. It's important. If she looks after us, then we can look after her [LA#2 009, female, employer, aged 60, proxy with user].

Exchanges involving money or gifts of more substantial monetary value were absent from the narratives of interviewees. The sole exception was one interviewee who was considering paying for the travel expenses of his PA to accompany him on vacations abroad at the house of a friend – something that the interviewee saw as much as a gift to the paid carer as well as a way of having someone to support him during the vacations. The closest thing to this was interviewees that had occasionally shared the cost of meals with paid carers, but these were also exceptions to otherwise fairly de-monetised gifts or exchanges. One possible reason for this is budgetary constraints. Many interviewees expressed not so much financial difficulties, but rather the wish to receive a higher DP. This could have precluded users from providing monetary gifts to those providing care to them. Similarly, home care agency rules also

precluded their carers from receiving money and furthermore LAs strictly monitored any money changing hands between DP users and paid carers. At the same time, however, most interviewees that expressed gratitude to their paid carers and reciprocated the care they received were still wary of expressing this through monetary payments:

I prefer it this way [managing the payment himself]. I don't mind and she deserves every penny and she works hard. She is, she even... It's down to six and half hours a week, well three quarters of an hour a day and then I think it's about one hour domestic, cleaning up and vacuum-cleaning. Well she spends two or three hours doing that. Of her own time. I don't give her extra money. (...) Sometimes she would ask me for money for the coming weeks instead of the fourth week, 'cause she is a bit short. I don't mind 'cause I know she'll do the work and she doesn't take liberties [LA#2 009, female, employer, aged 60, proxy with user].

Reciprocity was most of the time accompanied by feelings of deep concern or *advocacy* for paid carers. Many of the users that had somehow reciprocated in their relationship with paid carers also expressed a profound understanding of the difficulties felt by paid carers and referred to their concern for paid carers to be treated fairly. Perhaps unsurprisingly, reciprocity was closely associated with deeper relationships with paid carers (usually PAs). In the case of familial relationships, i.e. when PAs were themselves relatives, reciprocity was also present but as a motivation for caring. Two proxy interviewees clearly referred to their decision to become the main carer (one as a PA, the other as the main unpaid family carer) as partly driven by a feeling of reciprocity towards their now dependent in-laws who had helped them previously.

Reciprocity sometimes came closer to resembling a more altruistic behaviour from interviewees regarding those caring for them. One example of such behaviour was provided by the aforementioned interviewee who had chosen to manage payments to the PA himself to make sure she would get more money. Another example was of an interviewee who had willingly hired someone with a background of minor mental health issues as her PA in order to help this carer get back on her feet.

Just as telling was the absence of reciprocity in the narratives of users or proxy interviewees. These were mostly cases where the relationship with paid carers was defined on professional terms or described as being more superficial.

Differences and similarities between different groups

The presence (or absence) of reciprocity in the accounts of interviewees was arguably one of the main differences found between the three types of users.

Reciprocity was present in every single narrative of employer and relational-type interviewees, albeit expressed at different levels. For some relational type interviewees, the reciprocity took place within relationships of kin. In most employer-type interviewees, there were narratives of reciprocity involving flexible arrangements over schedules and timing of care. For example, it was relatively common for interviewees to adapt the actual schedule and timing of care (e.g. with the paid carer working more or less hours on a given day) not just around their own care needs but also to accommodate for the needs of the PA. Interviewees were happy to adapt their routines to accommodate for the needs of PAs who had other caring obligations, such as children or other paying clients. Reciprocity expressed as *time* was also present in the narratives of relational-type interviewees.

Other forms of reciprocity built around *gifts* or mutual social and psychological support as mentioned above, were also present in the narratives of both relational and employer interviewees. They were often accompanied by sentiments of concern or advocacy for the paid carers' own wellbeing, as expressed by the following excerpt of an employer-type interviewee:

I had a contract [with the carer] and although she was working for somebody else, nobody ever offered her a contract. She didn't even know about contracts. She was really in the dark. What she could have and what she couldn't have and what she was entitled to. For that reason I did it, because I thought that if you are good with your carers, they are good to you. (...) And I know it sounds weird to be talking about this, but there are so many carers out there that could be, I don't know, but from what I've seen, could be exploited [LA#2 003, female, employer, aged 60].

These somewhat higher forms of reciprocity involving material gifts and social and psychological support were not so much associated to a typology of interviewee, i.e. were not particularly associated with having a prior acquaintance employed as a PA, nor were they associated with tenure or social networks. Instead they were associated with deeper or closer relationships established with paid carers. The two cases where reciprocity had taken the form of material gifts, such as sharing paid meals, both involved interviewees which sought to

get companionship besides care from their PAs. For example, one of them was a relational-type user who had frequent contacts with relatives. The other , was an employer-type user who had had several PAs in the past and had reciprocated through occasional paid gifts with the one PA with whom she had established a closer relationship (for example, this was the same paid carer that had accompanied her to her husband's funeral).

Reciprocity was also clearly mentioned by employer or relational-type interviewees, in contexts where interviewees felt they ought to give something back to the PA or that they had a symbolic debt towards their paid carer:

In fact, I feel that I'm getting more out of her than what I'm paying her. I wish I had money to put on top of it as well, because she's done a hell of a lot more for me than I've ever done for her. That I can do for her! She had a pane in the car and it had to go to the garage and she said "Can I leave the car here..." she had a replacement car, but they had to leave her keys [with the interviewee]. That's the only sort of thing I can do for her. They came to my door. I can do... like take a parcel. That sort of thing. But, she does a heck more for me as a neighbour, than I can ever do for her. Hope one day... [laughter] I could! [LA#3 001, female, relational, aged 68].

In contrast, accounts of reciprocity of any kind – including those involving *time* – were absent from the narratives of purchaser-type users. When timings and schedules of care were adapted, this took place within the framework of the consumer-provider relationship between purchaser interviewees and agencies (this theme will be developed in section 6.5 below) and did not reflect any reciprocity towards agency carers. Similarly, there were no examples of gift exchanges with carers from agencies and it was clear that the chats and conversations that took place with agency carers were never understood as an action of reciprocation. In fact, a number of purchaser-type interviewees made it clear that the conversations held with carers from agencies did not involve discussions about working conditions or other issues pertaining to the carers, even though they recognised their sometimes difficult working conditions:

But this lot [carers from a previous agency] were always complaining about the treatment they were getting and everything, it was something we didn't want. We didn't want to hear about their moans, you know, we had enough of our own, you know [LA#3 002, female, purchaser, aged 80, proxy with user].

The absence of gift and time exchanges among purchasers partially reflected greater restrictions that agency carers had in accepting gifts or changing schedules as part of home care agency rules. Insofar as reciprocity is linked to the establishment of closer relationships, these restrictions could indicate obstacles faced by purchasers in establishing deeper relationships with their paid carers. Still, even reciprocity exchanges in the form of personal support, which could arguably still take place within care provided by agencies, were also absent from the narratives of purchasers, even those who reported greater continuity of their agency carers. Thus boundaries in these relationships were not only more defined, but there was also apparently less room or willingness to reciprocate.

6.4.3 BOUNDARIES IN RELATIONSHIPS

Overall sample

It was clear that establishing a rapport with paid carers was something valued by interviewed users, albeit in different ways, and that some among them went on to forge deep relationships with the persons delivering care to them. This proximity notwithstanding, the view that interviewees had of the relationship with their paid carers (whether PAs or agency carers) was hardly naïve. There were clear notions of setting boundaries or limits to the relationship with the paid carer, i.e. what was permitted and what was not, and also awareness of the power inherent to those relationships. Taken together, these provide a more nuanced meaning of relationships established in care.

The boundaries were more clearly set in relationships that were defined on a more professional level. In these more professional relationships, it was clear that the user held considerable power in the relationship, namely the power to end it. It was also clear that the relationship was confined to the time and space where care was delivered:

Whilst... if I was to bump into one of the carers, if I was outside my house going to a shop or something I would always say, "Hello, how are you?" and be polite. It's not as though they would just come and see me, do their job and then go and that's it, if you know what I mean. So there's... obviously they have to be professional and I treat them with respect, and I expect to be treated with respect in a professional capacity. They haven't come here to befriend me or anything like that, they've just come to care for me basically [LA#3 011, male, purchaser, aged 66].

For those who had deeper relationships with their paid carers, the boundaries of those relationships could become blurred, with users referring to their paid carers as friends or family-like. Despite this, even interviewees who had close relationships with their paid carers demonstrated being well aware that these relationships were first and foremost an employer-employee relationship. While there were cases where users had *followed* their paid carers when they had changed agency, there were also many references to users exiting relationships once these had become unsatisfactory, or whenever care provided was not up to standards. In other words, relationships seemed not to pose a too significant barrier to exit. Furthermore, shirking was a possibility which many interviewees were quite conscious of, as exemplified by one interviewee who had a relatively close relationship with her paid carers:

And they've both been with us a year now, because, again, we realised that we couldn't rely on one private carer, you know, because they mess you around. As soon as they think that you like them and their job is secure they will take advantage of you. So I thought that if we have two, they will always feel a little bit insecure, they might think that the other one will get more work and you know that works really well [LA#3 013, female, employer, aged 86, proxy with user].

The issue of setting boundaries in relationships was also very much present when interviewees discussed the reasons why they had not employed friends or relatives as their PAs – apart from the very few who stated that they simply did not have any relative or friend living nearby. On this subject, there were three main arguments set forward by interviewees: how to conciliate an employment relationship with kinship or friendship; constraints around burdening friends or relatives with their care needs; and the *shyness* involved in intimate personal care. It was not uncommon to find these arguments overlapping within the same narrative.

Regarding the first of these arguments, many interviewees expressed their reservations towards being able to manage employment relationships within the frame of existing friendship or kinship relationships. These interviewees were acutely aware of the power nature associated with caring – both as employers and as the paid carer, given the user's dependency on the paid carer, for example, for personal care. They expressed doubts about whether this could carry forward to a relationship based on kinship or friendship. They expressed concerns about how this power nature could *pollute* the other relationships. There were clearly issues around commanding a relative or friend to provide care, or using money to reward relatives or friends and how that could affect care or exchanges that otherwise

were based on intrinsic motivations (Frey 1998). A more articulated interviewee expressed this opinion when inquired about the possibility to employ a friend or relative as a PA:

Very interesting you say that, because... you are talking about relationships. Friends are friends for a set of parameters. When you are in a business arrangement, whatever it might be, the relationship is different, because there is power. In a friendship relationship the power is mutual, which is usually what makes the friendship work. It is not like that when money is changing hands. So to get a friend to do it, it would be a very difficult thing to do and I personally would not recommend it [LA#2 007, male, employer, aged 64].

There was however, a flip side to this argument. Employing acquaintances could also make it difficult to resist the temptation to over-rely on an acquaintance employed as a PA, especially if this acquaintance lived close by:

And my daughter was on the phone when the first one [doorbell went as children were playing outside her house] and she said "Phone the carer [name omitted due to confidentiality] and ask her to go out." And I thought no, she is not there for that. Even though she is a neighbour, she is not there for that. She's not my personal bodyguard or things like that [LA#3 001, female, relational, aged 68].

There was an element of self-interest in some of the arguments put forward to explain the reluctance in employing relatives or acquaintances. Some of the interviewees expressed concerns that their acquaintances would not be able to cope with the added responsibility. Despite this, the prevailing reasons seemed to relate more closely to predominant values about family or friends' responsibilities for caring for frail older people. Most interviewees expressed reservations or even deemed it inappropriate to burden their relatives or neighbours with their needs: *"But I wouldn't want to impose on them [the neighbours]. I think that there are some things that should be kept separate"* [LA#2 003, female, employer, aged 60].

Finally, there was also the issue of intimacy that certain care tasks involved. As seen before (section 6.4.1), when it came to strangers, i.e. paid carers (whether PAs or agency carers) that were not acquaintances, establishing some sort of rapport with the person delivering care was essential to receiving personal care of a more intimate nature. Regarding relatives, however, interviewees expressed the view that one needed either to be extremely close to a person, or have some emotional detachment in order to feel comfortable enough to receive or

deliver very intimate care. This again hinted at the complexity of the relational aspects of care. This last point is exemplified in the following two excerpts regarding personal care:

I think it's always difficult with your relatives when you're talking about personal care. Obviously if I had a wife then maybe she could provide that, but we separated so that is not an option. I have a daughter that lives a way away but she herself is disabled and she also has a family to look after, so it's rare that she could come to visit anyway [LA#3 011, male, purchaser, aged 66].

It was just because it's my mother-in-law, I think. I have to wash her and when she can't, I have to clean her. So that was hard at the beginning. But once you get into a routine it's a lot better. You distance yourself. I wouldn't do it if it was my mother. But I could do it to my wife's mum, which is quite strange [LA#3 009, female, relational, aged 79, proxy with user].

The existence and importance of boundaries in relationships is thus an important factor to take into consideration, for example, regarding the initial choices of interviewees – chiefly among them the choice not to employ acquaintances – but also regarding the preferences expressed by some to maintain more detached relationships with their paid carers.

Differences and similarities between different groups

Not surprisingly perhaps, the boundaries of the relationships were more clearly defined among the purchaser-type users where relationships with agency carers tended to be defined as professional. In this case, relationships were clearly delimited in time and space. For instance, former agency carers that called in to inquire about the interviewees' wellbeing long after they had ceased to work as their paid carers were viewed positively, but contacts outside working hours by current agency carers were frowned upon. At the same time however, the relationships with agency carers were framed in the context of the consumer-provider relationship established by the agency. This meant that the chats with agency carers, although appreciated as part of the relational aspect of care, would typically not include discussions about the carer's personal problems.

In comparison with purchasers, the plasticity of the relational boundaries was greater among employer-type interviewees, as they allowed for reciprocity and symbolic *gift exchanges*. Despite this, employer-type interviewees were aware that their relationships with PAs, no matter how close, were ultimately employer-employee relationships. Because some of them enjoyed very close bonds with their PAs, the boundaries would sometimes be stretched. The

following excerpt provides an extreme example of these blurred boundaries, but it is also somewhat of an exception since employer-type interviewees as the purchaser interviewees depicted above did not usually maintain contacts outside caring hours:

The carer that I've had she's never been to a funeral, but she has been to my husband's funeral to support me. She said she had never been to a funeral before and there she was with the whole black outfit and the people were "What's she doing here?" And she had the courage to be there for you and I think that's nice [LA#2 003, female, employer, aged 60].

Both employer and purchaser-type interviewees expressed reservations about employing relatives or friends as PAs on *relational grounds*. Interviewees from both groups reported that the nature of care (i.e. the tasks), but also their feelings about relationships, their own independence and that of their relatives, precluded them from relying on relatives or friends.

Issues around overburdening relatives were also raised by at least two relational-type users that employed former agency carers known to them, but not relatives or neighbours. The other relational users who employed relatives did not find the conciliation of familial and caring spheres to be especially problematic or at least they did not refer to these issues. It was often the case that children or grandchildren, often co-residing or living very close by, were employed as PAs, which meant that caring and payments were made within very close-knit relationships of kin. Despite this, there were no reports of potentially conflicting situations arising. It is worth noticing though, that these interviewees were proxy respondents of relatives with advanced stages of dementia, to whom this was likely to be less of an issue due to the condition of their relatives. For proxy respondents of relational-type users who employed relatives as PAs, the delivery of personal care was sometimes an issue that arose in their narratives. As for proxy respondents of employer and purchaser-type, there were also seldom reference to overburdening of relatives or difficulties in conciliating familial and caring spheres as many of them were anyway the main family carer (see section 6.6 for a more detailed account of the narratives of proxies on this issue).

The boundaries in relationships are salient to the main research question of this study on several grounds. Firstly, they provide important clues as to the initial choice, namely why some interviewees did not opt for employing relatives or friends when these were available. Secondly, they also contribute to understanding why some users, particularly purchasers, did not seek to deepen their relationships with their paid carers and why they were content with

having professional-like relationships. Boundaries thus attest to the complexity of the relational aspects of care.

6.4.4 SUMMARY OF THE MAIN ISSUES RELATED TO THE RELATIONAL ASPECT OF CARING

This section focused on the relationships that interviewees established or developed with paid carers, including how they perceived this relationship and how it impacted their experience of care. This also included the role played by reciprocity in the definition of relationships with paid carers, as well as limits to the relational aspects of care. The main findings can be summarised as follows:

- Relationships contributed to the perceived satisfaction or overall experience with care in two non-exclusive ways. Firstly, across all groups there was clear evidence of a common recognition of the instrumental importance of relationships – i.e. that relationships could contribute to care being delivered *when* and *how* users preferred it. Secondly, some users, however, also attached intrinsic value to relationships, particularly those who wanted companionship and proxy respondents of users with dementia.
- The differences in valuing relationships seemed to reflect the deployment choices of users. Those that valued relationships as an outcome had initially decided to employ a PA, which gave them more control over the choice of whom to receive care from and also more leeway in developing relationships.
- Interviewees and their paid carers developed a wide range of relationships. At one extreme, the bonds created with PAs could come to resemble family-like relationships with users and paid carers offering each other personal support and acquiring a profound knowledge of each other. Many other users referred to their PAs as their friends and as someone they trusted to make crucial decisions, such as hiring replacements. But relationships with paid carers could also be mainly defined on a professional basis, as was the case for most purchaser-type users, who also had reportedly less leeway in choosing their paid carers with agencies.
- The differences in the depth of bonds with paid carers seemed to reflect differences in valuing different aspects in relationships. Users who sought to have social interaction and companionship had thus established deeper bonds with their PAs. Users with more professional-like relationships with paid carers seemed content with the nature of their rapport, and had purposely meant to keep some distances between themselves and their paid carers (usually agency carers). These differences seemed to split along deployment of DP lines, with deeper relationships found among those

employing PAs and more professional-like relationships among purchasers, even after some time had elapsed in the caring relationships. Other factors, such as differences in living arrangements and social networks seemed not to have a significant impact.

- Reciprocity was a defining characteristic of relationships. Relationships between interviewees and PAs defined around kinship or friendship often involved reciprocal exchanges, expressed in time, or mutual exchanges of personal support, or the occasional gift, though not cash. With just one remarkable exception, gift exchanges were of limited monetary value. In these cases, relationships between users and paid carers were clearly defined as interdependent relationships (Kröger 2009). Conversely, reciprocity was mostly absent in the narratives of purchasers who had more professional-like relationships. This could also reflect greater restrictions that agency carers had in accepting gifts or changing schedules as part of home care agency rules.
- There were clear notions of the boundaries involved in the relationships between users and paid carers. Some employer-type users, purchasers and even some among the relational users that did not employ relatives or friends explicitly said that they did not want to cross the boundaries of different relationships. Some of the boundaries seemed to reflect deeply-routed values regarding caring responsibilities (England & Folbre 2003). Personal care of an intimate nature could also raise issues regarding provision of care by acquaintances. Boundaries were purposely more clearly set by purchaser users and this could help understand why they sought and were happy to have more detached relationships with their paid carers.

Summarising the contributions of this section to the research question and hypotheses being explored, the building of a rapport with the paid carer is important for the satisfaction of users, but in a complex manner. Some interviewees derived great satisfaction from the relationship itself and went on to develop close relationships with their PAs, with room for reciprocity and symbolic gift exchanges. These were interviewees that had been able to choose their own paid carers. Their narratives came closer to support the first hypothesis under study. Other interviewees, however, recognised relationships as *instrumental* to the delivery of care and to their satisfaction with care received, but they did not wish to replicate familial or close relationships. These users, mostly those who purchased care from agencies, had admittedly less leeway to choose their paid carers or to reciprocate in the same manner than those employing PAs, but they seemed content to have some distance with their paid carers. It was not evident that this second group of interviewees was less satisfied with the

relational aspect of care they were receiving. Nonetheless, it seems evident that there was some relation between the initial choices made (see section 6.3.2), i.e. having greater control over the identity of the paid carer through direct employment, and attaching an intrinsic value to relationships.

The perceived *instrumental value* of relationships to deliver care alluded to above pertains very much to the second hypothesis under study, i.e. how choosing the paid carer could impact the leeway in defining the delivery of care tasks. It seems clear at this point that, at least as far as personal care was concerned, developing some kind of bond with the paid carer could improve the experience of receiving care. The next section expands this and analyses in greater depth how care was negotiated and delivered.

6.5 DEFINING TASKS AND THEIR DELIVERY

The second hypothesis under analysis in this study questions whether different possibilities of purchasing care from agencies, or hiring a PA, could affect the leeway users have in defining when, what and how care is delivered. In this context, this section will review the interviewees' accounts of how the delivery of care was negotiated and carried out under DPs. This includes the definition of the duration and schedules of care – i.e. the dimension of choice *when* – as well as the definition of the care tasks themselves – i.e. the *what* and *how* care is delivered. These constitute the two headings of this section.

6.5.1 DEFINING TIMINGS AND SCHEDULES

Overall sample

It is worth bearing in mind that issues generically related to *time* were among the most common voiced complaints by interviewees regarding LA-managed care (see section 6.3.1). This was therefore a theme of particular importance to them. As a whole, interviewees expressed what they considered to be a visible improvement in their satisfaction with the overall timing of care.

According to their own accounts, several interviewees from different user-types said that having the ability to choose a particular agency or a PA had strengthened the accountability of paid carers to perform their tasks adequately and on time. The increased punctuality of care had an obvious positive impact on the wellbeing of interviewees. Users felt they could better manage their own life and condition with the certainty that care would be delivered when required. Examples include the paid carer coming in at the designated time to provide

breakfast, or coming in earlier to help the user get ready to go to a hospital consultation. To some extent, this timeliness of care added to the interviewees' sense of independence. Having to wait for a carer that might not arrive had often been a deeply disturbing experience that reminded users of their lack of independence:

But I found in my dealings with the agency, sometimes it's not their fault, sometimes it's simply this "I don't give a damn", that I'm sitting in there waiting to be brought on to the chair to clean myself, to be brought to the shower and etc. and it's one hour late. It's one hour and half late. Two hours late! [LA#2 010, male, employer, aged 71].

The timeliness of care could in part be attributed to new caring arrangements enabled by the DPs, such as when interviewees had decided to employ their own PAs. The interviewees that continued to purchase care from home care agencies however, also reported an improvement in the timeliness of their care. Not only was communication streamlined, i.e. they could simply contact the agency directly rather than going through the LA's social services, but users could also more easily change agencies when unhappy about the care received. Some actually did that before eventually finding a suitable agency. There was also an overall feeling that home care agencies were somewhat more responsive.

Improved timeliness was only one of the enhancements reported by interviewees regarding time. The other was added flexibility, which could mean an increased scope to define schedules of care, i.e. when care would actually take place; increased possibility to deviate from those schedules to accommodate for changes; and increased possibility to change the duration of care. Each is analysed in turn, together with the extent to which these improvements were influenced by the possibility to choose one's paid carer. This refers to the second hypothesis under study: that different possibilities to choose a paid carer impact the leeway users have in defining what, when and how care is provided.

Most interviewees felt they had quite a fair degree of leeway to define their schedule of care, namely starting times in the morning or at later times during the day. This was particularly important for interviewees as they could shape care to their daily routines, also in the case of proxy respondents that were the main family carers, albeit not the PA:

Yeah, to think about what mum wanted and what I wanted as being the full time carer, what break I wanted, and that was, for example, not coming round sort of seven in the morning getting mum... Actually mum's got the carers there, I know

she's there and I could go and put my washing on and go to the gym for two hours and then I come round to mum. Or I might get my washing... so that, having the choice of how I wanted that plan worked out perfectly for me. And then I could be with my family 'cause my daughter was still young then [LA#3 004, female, purchaser, aged 74, proxy with user].

You get into like this routine of sort of doing things, you know. Like if, say, she doesn't want to be washed first thing in the morning, say she got up a bit later or something, I can say do some housework or whatever and when she wants to get up then I can sort of feed her. So you know, you sort of work round her sort of thing [LA#3 003, female, relational, aged 92, proxy with user].

Occasionally, the need arose for users to adapt their schedules to those of their paid carers. This happened more often with PAs that were employed by users than with agency carers, as the latter could more easily manage with their staff (e.g. by sending in a replacement). In these instances where interviewees had adapted to the paid carers' schedule, however, they did not express this as a complaint or constraint and seemed content to do these adaptations. Two explanations were put forward for this. First of all, these adaptations were agreed in advance and adhered to, i.e. there was no issue of reliability. Secondly, these adaptations were often seen as part of the wider reciprocal exchanges discussed earlier (see section 6.4.2), in which case the reciprocation involved *exchanges of time* within a caring relationship. As part of these exchanges, PAs were often very flexible in their working times even when they were not co-residing relatives or neighbours:

No, she is here and she will come to me. You know, she is here at half past five one morning 'cause I had to have the infusion to have these exams and drugs. And I said "You don't have to come. If you come in the evening I can get myself sorted.", "No, no." she said and at half past five there she was. Yeah. So, the flexibility works for both sides. You know, if she has an emergency she would pop up and say "Can I come a little bit later?", "Of course." Or if it's somebody else that she had to visit, "Don't worry about me. You can come in later. You just sort it out and get that done." So... [LA#2 003, female, employer, aged 60].

If there was one complaint that interviewed users had regarding the definition of caring schedules, it was the lack of sufficient funds or time in their care plan.

Flexibility also meant the ability to adapt at short notice to changes provoked by the interviewees' evolving health condition or other motives. Agencies were for the most part able to accommodate to changes at relatively short notice, but the flexibility was much more pronounced when users employed their own PAs. Once again, this flexibility was considered very important for interviewees to achieve a sense of "routine" or "normality" in their lives – i.e. it was an important point in regaining their independence. It was particularly important in the context of health conditions or symptoms that could not always be timed or scheduled.

Interviewees also reported on their ability to determine or adjust the length of care provided. Unlike some of the practices of LA-managed care, DP users could top-up their payments out of their own pocket in order to get more hours of care. Many did just that, particularly when purchasing care from agencies. For some users, adjusting the length of care, for example, by accumulating hours of care or "banking hours" within the limits set by the LAs, also afforded them the possibility to work around the limited care hour slots or to receive domestic care that could take longer to carry out or use the accumulated hours to socialise – particularly if they were employing PAs:

I do find it difficult with so few hours and the time slots because it's half an hour in the morning and a quarter in the evening. That you can do, but with an agency you couldn't. They just wouldn't be there [LA#2 003, female, employer, aged 60].

So, what I'll be doing with Sharon, when the time comes, I will just say "Finish the things half an hour earlier every day, collect the hours and on the Sunday take us to Southampton then." You're with me? This is the beauty of DPs! [LA#2 010, male, employer, aged 71].

This flexibility could go as far as allowing users to get more hours than their plan stipulated, particularly once they had come to establish a more long-standing relationship with their paid carers. This could be seen as yet another *instrumental value* of relationships.

Differences and similarities between different groups

There were apparently no distinguishable differences in perceived satisfaction with schedules and timings of care across the sample. The existing complaints were mostly confined to sometimes having limited budgets or hours of care allocated to users. In general, employer-type users had found agencies willing and able to accommodate for their needs and preferences in terms of schedules, particularly if given sufficient advance notice.

Employer and relational-type users had, however, greater leeway in defining the schedule and timing of their care, i.e. they had greater flexibility regarding when to receive care. They seemed to be able to change care schedules at a shorter notice, or have PAs sometimes coming at slightly odd hours, albeit usually as an exception rather than a rule – as the example above of a PA that came in at half past five in the morning. The flexibility also included the possibility to accumulate hours more easily, even with the constraints imposed on unspent DPs by LAs (see section 6.1), or have PAs deliver care for longer hours than they were supposed to:

What we do when I'm not using one hour in one week we have like bank hours. So if I need my cupboard cleaned I can just say to my carer "Could you please, if you can stay a bit longer on Saturday?" and she will just spend an hour doing that. So that works [LA#2 003, female, employer, aged 60].

This ability to get more hours of care than they were supposed to had in at least one case allowed an employer-type user with a very limited number of hours to actually be able to receive care from a PA she employed after being refused care by a number of agencies. In another case, an *expert user* (i.e. someone with a fairly good knowledge of the workings of DPs) had chosen to have part of her care package as a DP in order to employ her present agency carer as a PA and thus benefit from more hours of care. The flip side of this flexibility is that employer and relational-type interviewees sometimes had to adapt their schedules to those of PAs, which was seldom the case with agency carers.

The flexibility around times was particularly appreciated by proxy respondents of users with advanced stages of dementia – two of whom were themselves the PA – whose relative's conditions did not always suit scheduled care: *"If she wants to get up at nine, we get up at nine or early hours in the morning and once she is asleep, she's asleep. She tends to sleep a lot longer now than before"* [LA#3 009, female, relational, aged 79, proxy with user]. In these cases, flexibility was also aided by the fact that PAs were co-residing with users.

The negotiation of schedules between employer or relational-type interviewees and their PAs was often based on informal arrangements. In these arrangements, it was common to find clear notions of reciprocity alluded to before (section 6.4.2). When negotiating care schedules, reciprocity was present not only in the form of mutual flexibility in time, but also as symbolic exchanges of gifts:

I mean, she works so hard! Sometimes she comes in the morning and she works about three, or three and a half hours and if something happens or whatever, she rings me up and tells me "Look, I can't come tomorrow. Do you mind if I come at three o'clock instead?". It's fine. And that's how we work. And it's a good relationship [LA#2 007, male, employer, aged 64].

In contrast, home care agencies were generally perceived as accommodating to the interviewees' wishes, but the informal arrangements and extreme flexibility of times reported by employer-type interviewees were much less present. In the former case, care schedules were agreed within the context of consumer-provider relationships and did not involve *quid pro quo* changes directly settled with agency carers. Similarly, there was no reference to carers employed by agencies overstaying their allocated times. Instead, users often referred to the possibility to top-up the care hours they received by paying out-of-pocket for additional hours from the agency – a possibility that was not available before moving to DPs:

And literally it is one minute passed [the hour] and "I've got to go! I've got another client. Bye!" and she was out the door as quick as she could. I told them that if they had some more time we would increase what we are paying to get a full hour. To top it up. At least [with DPs] we've got that option now. But before we could never top it up and it's very difficult to get someone privately to come just for 15 minutes, even if the agencies do 15 minute times for private. While if you call them they are happy to top it up [LA#3 005, female, purchaser, aged 85, proxy with user].

Regarding the timing and duration of tasks, the findings reported above seem to confirm the hypothesis that the different deployment options afforded by the DPs had an impact on the leeway different types of users had in the definition of care they received. Employer and relational-type users had thus greater leeway in defining timings and durations than purchasers. The timing and duration of tasks was sometimes agreed in the context of reciprocal exchanges, but one should not entirely credit the rapport established with the PA for this increased flexibility. The apparent smaller flexibility of home care agencies regarding timing also reflected the greater constraints faced by agencies, for example, regarding the possibility to accommodate for last minute time changes.

6.5.2 DEFINING TASKS - OR WHAT AND HOW CARE IS DELIVERED

Overall sample

A significant minority of interviewed users had previously expressed dissatisfaction with the tasks that agency carers had not carried out when on LA-managed care (see section 6.3.1). Once on DPs, however, the negotiation of tasks with paid carers (whether PAs or agency carers) was not an issue of discontent or perceived conflict. Interviewed users felt as a whole that they had more control over what care they received and how they received it.

Interviewed users were able to determine what care they received and this sometimes included tasks that were not initially foreseen in the care plan or funded by the LA, for example, housework or social outings, but which users felt they had a need for. In some cases, users had not been wholly satisfied with their care plan and the DPs gave them more leeway in determining what needs they wanted to be addressed by enabling them to directly negotiate this with their PAs or agencies. This was often achieved in conjunction with the ability to bank hours, as previously stated. Narratives around the ability to get housework help (e.g. cleaning) – which had not been covered by care plans – also abounded among the sampled users, often in opposition with previous experiences where they had been refused this type of support while on LA-managed care. Interviewees mentioned no case of refusal to carry out tasks with their current PAs or home care agencies. Sure enough, even when on DPs, some interviewees had come across refusals or less accommodating PAs or carers from home care agencies. However in those cases they had been able to change PAs, agency carers or agencies themselves.

This ability to determine one's own care needs (or those of relatives in the case of proxy respondents) was important, as dissatisfaction with the assessment of needs were, together with those linked with budgetary constraints and how to use DPs, among the most frequent complaints regarding the process of receiving a DP. For a number of users that had used DPs as an opt-out of what they considered to be unresponsive or inadequate LA-managed care, this ability to determine what exact care to receive was very much appreciated:

For me the care package was to one side and I was sure it wasn't what my mum needed. My mum needs to make sure that she has nutritional meals, and regular drinks, and that she socialises, very much. And then I looked at what I thought she needed and the difference [in the care plan] was this thing about getting dressed and I didn't think that was necessary. The carers always wrote that they didn't

have any involvement in that, she was always resisting that. And then I thought that the [name of provider omitted due to confidentiality] is actually what she needs and family filled up the other gap [LA#3 012, female, purchaser, aged 81, proxy without user].

The interviewees were also able to better tailor the tasks to their changing needs and routines. This could include determining how their medicines were taken or apparently more trivial things, such as determining how often they wanted to take a bath, but that users felt were important to their perceived quality of life or to maintain decisional autonomy. This was another aspect of the extra flexibility that interviewed users attached to DPs: the ability to more easily and quickly change tasks to better fit their needs. Before, it was not uncommon for even small changes to care tasks to require approval from LA staff. These changes could now be negotiated and settled directly with home care agencies or PAs. In the latter case at least, there seemed to be a fair degree of informality in the negotiation of tasks:

Well, it's actually not too bad under the DPs. Before you used to have to call social services, social services to approve and then change and they would have to contact the agency and the agency would get in touch with us. (...) So we can contact the new carer [name omitted due to confidentiality] directly and she is very flexible. You just let her know and then she can come in a bit earlier in the evening or stay a bit longer to do things that are needed. And she always does the things that are needed [LA#1 001, female, employer, aged 72, proxy with user].

Beyond the greater leeway in defining their care needs and adapt tasks to those same needs, the narratives of interviewees presented also examples of how the relational aspects of care influenced the care they received. Firstly, continuity of paid carers allowed them to gain knowledge of the user's care needs and personal preferences (see section 6.4.1). There were a number of narratives where users mentioned the often disturbing need to teach each new paid carer how to do things the way they wanted or preferred, or how, on the contrary, they valued PAs or agency carers that took the trouble of learning one's preferences:

The first people I was with, they sent different people on different days and they weren't used to things in the flat and I had to show them everything [LA#2 002, female, purchaser, aged 81].

[Interviewer]: It's a relationship you've built with time or...?

[Proxy respondent]: You build, or mum has new carers come in and they shadow the old carers and then they realise "Oh this is the way she does it" [LA#3 004, female, purchaser, aged 74, proxy with user].

The rapport established with paid carers (whether PAs or agency carers) was also important in two other ways: to ease negotiations with paid carers and to improve the experience of receiving personal care. A number of interviewed users found it easier to negotiate care tasks or to get paid carers to do tasks that were "*perhaps not entirely in her remit*" [LA#2 008, female, relational, aged 75] once they had gotten to know them a little better. The rapport established with the paid carer more often facilitated the negotiation of tasks – for example, when users were not too self-confident, or felt unsure of how to handle these negotiations – than acted as an obstacle. One instance could be because the user and paid carer could become too close. Again, these negotiations could be imbedded in strong reciprocal relationships:

Well it started off with just doing the... helping me wash and preparing some breakfast and as we got to know each other and I gave him advice on certain things that he needed to sort out in his life, and he had problems with his house and building and that, and he used my knowledge to meet the right people in order to get it sorted. Our relationship grew and obviously the more we helped each other the more he's helped me. If I said to him now, "Will you clean that mirror for me?" he'd do it. He'll go down to the shops, do the shopping, come back, put it in the freezer, whatever needs to be done he'll do it [LA#2 005, male, relational, aged 61].

As mentioned earlier, the intimacy of personal care could be a powerful issue in determining who was best suited to carry out these tasks (see 6.4.3). On this issue, there were again consistent narratives about how the quality of personal care, as perceived by the users, had improved significantly when receiving care from someone they trusted or personally liked, or that knew how to deliver personal care according to the preferences of the user:

(...) when you're disabled as much as I am, you need to build up a relationship with your carer and then your carer gets to know you and what your needs are, and where he needs to help you, and where you can do it, it's easier to do it yourself. And of course in the manner and the way you like them done [LA#2 005, male, relational, aged 61].

Before addressing the issue of potential differences in the definition of tasks between the different types of DP users interviewed, this section already illustrated some salient findings in the context of the research question of this study. The rapport established with the paid carer (particularly PAs) had allowed users to improve the breadth of care tasks that they could receive with DPs – i.e. users could receive care beyond the usual “remit” as the above-quoted user said – and in this sense they could better match the tasks to their needs. Beyond extending breadth, however, relationships could also fundamentally contribute to improving the quality of care as perceived by the user, of which personal care was the most compelling example.

Differences and similarities between different groups

In the narratives of purchaser-type users, there were noticeably less references to some tasks that were often detailed in the narratives of the other types of users, such as housework help. There were also occasional references to the perceived lesser flexibility in using DPs for certain tasks when receiving care from agencies, for example, there were no references to social outings as part of the care received by purchaser-type users.

Despite this, the ability to determine tasks, to receive care that might not be explicitly covered in the care plan, and to feel that the agency carer was knowledgeable of one’s needs and preferences, definitely improved as interviewees spent more time with agency carers. In this respect, purchaser-type users came to resemble more the other type of interviewees: *“But I do say for them to do more set of things now than I did at first perhaps. With experience, you know how often... but that’s about it”* [LA#2 001, male, purchaser, aged 71].

Among employer and relational-type users interviewed, there were more often references to tasks such as domestic chores, particularly more heavy tasks, and when relationships with PAs were closer, also social outings. There were cases of interviewees explicitly mentioning that their PAs were willing to do tasks that previous agency carers had refused to carry out, but these refusals had often taken place while they were still in LA-managed care, so the comparison is somewhat different.

While purchaser-type interviewees generally settled care tasks (as well as schedules) directly and verbally with home care agency managers, the negotiation of care tasks between employer and relational-type-users and their PAs was even more informal. As mentioned before, agreement on the setting of tasks often involved reciprocity or gift exchanges that were not present in the narratives of purchaser-type interviewees. The relational proximity

often helped to determine tasks without conflicts. Defining the boundaries of relationships while defining care tasks could, nonetheless, sometimes be an issue for some relational-type interviewees and employers with closer relationships. For instance, one relational interviewee who had employed a neighbour as the paid carer expressed doubt about what was done under the remit of “neighbourly help” and what fell under the paid caring relationship.

Across the sample, proximity also helped to improve the perceived quality of care received, namely when paid carers were able to understand the preferences of users regarding how care was to be delivered. There was, however, one exception: personal care of an intimate nature. For those employing close relatives there could be an issue with too much proximity in the delivery of personal care (see section 6.4.3). Kinship relationships, and in some cases gender, could be a barrier to the provision of care of an intimate nature, for example, by sons to fathers or mothers. Some purchaser-type interviewees also expressed strong preferences regarding the gender of their agency carer when it came to the delivery of personal care. This was not portrayed as an issue however, as home care agencies – limited as they were in the leeway afforded to users in the choice of their paid carers – often accommodated users’ requests regarding the gender of their paid carers.

The findings of this section therefore provide some support to the hypothesis that employer and relational-type users had some more leeway in the definition of what care to receive and how. This was particularly evident regarding some types of care such as social outings. To some extent, this reflected the fact that as direct employers of their PAs, employer and relational users faced fewer constraints and had more power to determine the content of care. Relationships, however, also played a role in this. The leeway to define care and to get paid carers to provide other tasks expanded with time, and with it the strengthening of the relationship. Moreover, purchasers also made reference to this in their narratives, whenever continuity of agency carers existed, which strengthens the evidence that relationships can contribute to increased leeway in the defining of care tasks.

Possible confounding factors behind the definition of tasks

Besides continuity, i.e. the tenure of the paid carer, other factors, mainly related to the characteristics of users, were also systematically explored in order to explain differences in the definition of tasks. Chiefly among these factors were place of residency (in which LA was the interviewee residing), living arrangements and social networks, health condition and age of the interviewee. The first sought to explore possible differences arising from the fact that

one LA had not yet implemented PBs, which could have implications in terms of the leeway in defining tasks (see section 3.2.2). As for the other factors, they mostly referred to the possibility that interviewees with better health, who were younger, with stronger social networks or living with their spouses or children could better negotiate tasks with their paid carer, either because they were not as frail, or because they could rely on their spouse or wider social networks to negotiate on their behalf.

LA#2 had not yet implemented PBs at the time of the interviews, which could mean that interviewees from this LA could potentially have less leeway in receiving care other than personal care. However, the narratives of interviewees (or their proxies) from the different types of groups of users residing in LA#2 did not show significant differences from their counterparts in the other LAs. For example, PAs employed by users in LA#2 also regularly performed household tasks and/or tasks that clearly went beyond personal care:

[User]: So, what I'll be doing, when the time comes, I will just say "Finish the things half an hour earlier every day, collect the hours and on the Sunday take us to Southampton then." You're with me? This is the beauty of DPs!

[Wife]: As long as they are doing their job...

[User]: You don't do that if you were with an agency. And we are not cheating anybody. We are not doing anything wrong. Because I told the social worker and he said to me "This would enable you to use your hours how you see fit". [LA#2 010, male, employer, aged 71]

As exemplified by the above quote, this was explained by the fact that restrictions imposed on the possibility to accumulate DPs in LA#2 – a key factor, together with relationships, in allowing for tasks beyond personal care to be delivered – did not seem to be particularly more stringent than those enacted in the other LAs.

In the narratives of users it was not evident that co-residing with the spouse or having a larger social network had a significant impact on the ability to negotiate tasks. There was no explicit reference to spouses or children mediating the negotiation of tasks with paid carers. The exception was those with advanced stages of dementia, where the negotiation of tasks was undertaken directly by their proxy respondents (an issue further discussed in section 6.6). As mentioned earlier (see section 6.2), employer-type users were in general younger than the users sampled in the other groups, namely purchasers. This could have constituted an advantage in the negotiation of tasks with their paid carers as it could mean less frail and more articulated users.

6.5.3 SUMMARY OF THE MAIN ISSUES RELATED TO SETTING TIMES AND TASKS

This section analysed how care tasks and times were negotiated between users and paid carers. It explored potential differences between the types of DP users in the sample, to gain better insights into how hiring a PA could (or not) translate into more scope to define care.

The main findings of this section are:

- Users employing PAs seemed to have a greater degree of agency over the definition of times. This included care provided at very early or late hours and a greater degree of flexibility in tailoring schedules to the changing needs of users, but also greater possibilities to *bank hours* that could then be used for more time-consuming tasks. Employing a PA had also enabled users to get more care hours than they paid for in more than one occasion, which was not possible under home care agencies.
- In defining care tasks, relationships could contribute to improve the subjective experience or satisfaction with care. Relationships allowed users to widen the breadth of care tasks, as they referred to being more comfortable with requesting different types of care as their rapport with the paid carer was built. Relationships also enabled paid carers to recognise the needs, moods and preferences of users regarding what care to receive and how. Finally, relationships could also contribute to enhance the subjective quality of care received, particularly in the case of personal care.
- Interviewees that employed their own PAs arguably had greater leeway in defining care tasks. Users employing PAs could extend the care tasks to include less conventional types of care and thus respond to a wider range of needs, such as socializing. Similarly to interviewees that had employed their own PAs, purchasers also recognised that as their relationship with agency carers evolved, they also felt more confident in asking for care more tailored to their preferences.
- The provision of care to employer and relational-type users was often negotiated informally and included reciprocal exchanges in terms of time, but also in the context of defining unconventional care tasks.

To conclude, this section presented strong evidence that employing a PA extended users' leeway to define care tasks and times. To some extent, this reflected the fact that employer and relational-type users were the direct employers of their paid carers and did not experience the constraints faced by home care agencies in providing certain types of care or in changing care schedules to respond to sudden requests for changes in the delivery of care. Furthermore, they also had greater leeway to accumulate care hours and use them to get

certain types of more time consuming care. There was, however, also a relational component to this. As relationships evolved, also with agency carers, interviewees felt they gained greater control over the definition of care tasks. Moreover, the way they perceived the quality of care delivered to them, particularly personal care, was very much influenced by establishing a relationships with the person providing care. In that sense, it seems that relationships could influence the co-production aspect of care.

The past sections have described the findings emerging from the narratives of interviewed users around themes relevant to the hypotheses under study. This analysis has used a typology of users – purchaser, employer and relational – derived from the literature review (see Chapter 2) and from the deployment options of DPs (see Chapter 3) to draw comparisons and deepen the analysis based on the differences and similarities between the types of users. Another typology of users emerged, however, from the data – one that cuts across the three types of users described above – and this was users with dementia. The next section details the analysis of this group and how the particularities of their condition influenced the choices made. As many of these interviews were based on proxy respondents' own accounts, the next section analyses issues raised by the use of proxies.

6.6 RELATIONAL AND EXPERIENCE GOOD NATURE OF CARE IN THE CONTEXT OF DEMENTIA

A significant minority of interviewees were users with dementia (see section 6.2), and their symptoms varied from mild cognitive decline (mostly affecting memory) to being confined to bed. In these cases, the decisions regarding take-up of DPs, choice of deployment option and related choices (identity of the paid carer, tasks, timings) was likely to have been a joint or devolved decision with their close relatives who were interviewed as proxy respondents. Furthermore, users were often frailer and care often posed other problems such as challenging or at least uncooperative behaviour, as well as arguably less stable schedules or limited ability to time some needs to the paid carers' visits. This section describes the findings of proxy respondents of users with dementia regarding the decision leading to the DP and choice of deployment (e.g. PA or home care agency), as well as the role played by the relational aspects of care and the negotiation of tasks (the dimensions of choice regarding *what, how* and *when*).

Recalling information displayed in Table 6.3, users with dementia included all of the three types of users: four of them had purchased care from home care agencies, two were employer-type and three relational-type users. There was therefore enough range of

variation in the use of DPs by people with dementia to ensure their salience to the hypotheses under study.

These interviews featured proxy respondents – their close, often co-residing relatives – although at least in the milder cases of dementia the users were not only present in the interview but also able to transmit their views or corroborate those expressed by their proxy respondents. In two cases, the proxy-respondents were also the paid PAs of the users. As discussed earlier (see sections 5.1.4 and 5.1.5 in Chapter 5), by relying on proxy respondents, some of the answers may actually refer to the choices or motivations of proxy respondents rather than users, in which case the findings are stated clearly as pertaining to proxies. In other occasions or themes, it was less clear whether proxies were talking on behalf of users or conveying their own opinions. In these situations, it is likely that the findings still mostly reflect the views of proxy respondents and they are referred to as such. Nonetheless, in the course of the interviews, it was sometimes obvious that proxy interviewees were reflecting on their relatives' preferences – some of which had been stated when they still had most of their cognitive functions intact – and the findings in the text are in these cases clearly stated as referring to users with dementia. These issues pertaining to proxies' responses, and how closely they might reflect the views of users, are explored in the following three sub-sections.

6.6.1 DECISION LEADING TO DP AND CHOICE OF DEPLOYMENT

Among interviewees with dementia and their proxies, there were three main circumstances that had surrounded the decision to opt for DPs: exhaustion of the family carer; complaints about LA-managed care received through home care agencies; and strong preferences on the place of care (the dimension of choice *where*). Each is analysed in turn.

Most users with dementia had already been very frail before their contact with DPs and thus unable to care for themselves without the strong involvement of a family carer. This arrangement began to collapse or came under increasing pressure as family carers felt exhausted from the burden of care, unable to conciliate their care with paid work or with care for other younger relatives. When the contact with social services was eventually made and DPs suggested, proxy respondents, that were also family carers, recalled that this came when they were feeling overburdened and often at the edge of collapsing emotionally. In this context, contact with social services had been led by family carers.

Some users had already been receiving care from home care agencies, mostly LA-managed care, although in one case, (agency) care was being paid for privately as the family had

sufficient financial resources not to qualify for publicly-funded (means-tested) care. In these cases where users were already receiving care from agencies, the strongest complaints evolved around two issues: timing and continuity of care.

While other interviewed users had complained about unreliable care regarding the often tardiness of agency carers (see section 6.3.1), there was another dimension to these complaints in the case of users with dementia. Interviewed users and their proxies had found it difficult to tailor schedules of care to often changing needs and timings, regarding not only bathing or using the toilet (i.e. personal care) but also eating. They required a flexibility that most agencies were not apparently able or willing to provide. This was a distinct feature regarding other users interviewed, i.e. those without dementia. Lack of punctuality only heightened the dissatisfaction with lack of control over when care was delivered:

[Daughter]: It was stressful to get her up when she was fast asleep and then get her to bed again.

[Son-in-law]: They used to come in at eight o'clock or half past eight regardless of her being awake or asleep, whilst I can be here from 8 till 11. It all depends on her sleep patterns, if she is asleep or awake this morning or in the afternoon [LA#3 009, female, relational, aged 79, proxy with user].

Particularly at early or late hours in the day, proxy respondents recalled that the experience of having to wake up their relatives could be very distressful both for them and the user. This was compounded by the lack of continuity that also featured prominently in the narratives of people with dementia or their proxies. The lack of continuity prevented users from recognising agency carers and feeling comfortable receiving care, but also prevented agency carers from forming a bond with users that was deemed in very high regard by proxy respondents and confirmed by some users:

The carers that were coming were awful, they didn't speak to mum. The ones that were coming, they need to come in and say, "Hello [name omitted due to confidentiality], how are you?" And make... they wouldn't get much response but they might get a smile. She'll know that they... you know... [LA#3 010, female, purchaser, aged 87, proxy with user].

When confronted with these complaints or with family carers breaking down, users had often been offered a place in a nursing home by the LA. This, however, was something that most users and proxy relatives interviewed felt very strongly about. The decision to use DPs, and in

fact the decision on how to deploy DPs, was very much driven by the wish to remain and be cared for at home. This was a very strong motivation underlying the narratives of proxy respondents. It was confirmed when possible by users with milder dementia present during the interviews. This was not found among the other interviewed users. By keeping their relatives in their own homes, proxy respondents seemed to express not so much their own views or preferences, but rather those of their relatives with dementia who preferred a *home-like environment*. Proxy respondents referred how in the past their relatives had expressed their wish not to go to a care home and thus proxy respondents felt they were following their relatives' preferences. Besides respecting their relatives' preferences, proxy respondents had in general a deeply ingrained conviction, sometimes borne out of experiences with respite care, that their relatives' cognitive ability would rapidly deteriorate if they were to be moved outside their familiar surroundings:

Anyway, they [pause] I wish I hadn't done it. They took her into respite and they kept her there for two weeks. We had a meeting and they told us that they were going to keep her in permanently and I had to fight to get her out and I was so upset with it all. (...)

And for two weeks, as I say, she was so much worse when she came out. When she went in she was walking about and it breaks my heart to see her because now she virtually faded away. I can't get her up on my own at all now so I need care [LA#3 010, female, purchaser, aged 87, proxy with user].

I don't think she would have lasted so long if she had gone into a nursing home. She used to go to one, when she was going to respite. She used to go in for two weeks and it used to take her another two weeks to get her back into the routine. So we stopped that [LA#3 009, female, relational, aged 79, proxy with user].

Against this backdrop, proxy respondents and users' decision on how to deploy the DP was apparently driven foremost by strong preferences to remain at home. Other reasons set forward by interviewees were to ensure adequacy of timings and guarantee continuity and the possibility to establish a rapport with the paid carer.

The decision of whether to employ a PA (acquaintance or not) or purchase care from a home care agency was also sometimes driven by budgetary constraints. Proxy respondents often referred to the difficulties in paying for sufficient care from agencies as their relatives' condition could require long hours of care that their DP amounts could not cover fully. While there were quite often references to users in general preferring to have more hours of care,

this was seldom voiced as a key reason for choosing agencies over PAs (or vice-versa) or for employing relatives or friends. In the case of people with dementia, budgetary constraints featured much more prominently in the narratives concerning decision-making:

Then social services came and they interviewed us, and we had a social worker, and it went to the panel, and we were awarded three hours a day of care, the cost of it, which does not pay for an agency. I was hoping it would pay for an agency at the weekends (...) and I thought "Great! At least that would pay for care with an agency." And it turned out it wasn't enough. So we have private carers and they are good, for two reasons. One is we can afford them [LA#3 013, female, employer, aged 86, proxy with user].

That is another reason... I couldn't afford really to get carers in, and then when I was told about the individual budget and whatever, because it was..., to be fair it was becoming a big strain on me, especially when mother-in-law [name omitted due to confidentiality] started to get a lot worse [LA#3 006, female, relational, aged 80, proxy without user].

Given the prevalence of proxy respondents among users with dementia, one salient question is whether the initial decision regarding the deployment of the DP mostly reflected the perceived users' preferences or those of the proxies. The specific analysis of the narratives of proxies regarding the initial choices seems to indicate behaviour that comes closer to being altruistic, or at least driven foremost by concern for their relatives, rather than by strict pursuit of self-interest. Some examples illustrate this point.

As it is apparent in some of the earlier-quoted excerpts, proxy respondents often faced non-cooperative attitudes from LA social services, which sometimes quite strongly argued in favour of institutionalising their relative. At least two proxy respondents recognised that keeping the relative at home had only been possible due to the strong-willed intervention of the family. Remaining in one's home and ensuring flexibility of care schedules was only possible with a strong family backup in all but one case, where the user with mild dementia was still able to live alone in her own house. In all other cases, relatives were the main carers, even if they were not the PA, or if they had purchased care from home care agencies. Being the main carer had often involved rather painful decisions by relatives, such as abandoning paid work or juggling care between their older relatives and younger children. In these cases, concern for their relatives, respect for their perceived or previously stated preferences,

reciprocity for past help and what could be termed as feelings of *duty*, seems to have overcome the relatives' own narrow self-interest in the decision-making process:

There was a choice of people, these care agencies but I like them because actually they were dearer than the council – I think it's all the same price now – and I kept with them because he liked the carer and I liked the agency, and I wasn't bothered with a few pounds because I wanted the best possible care for him. [LA#3 008, male, purchaser, aged 96, proxy with user]

She [mother-in-law] helped us out when my wife was ill years ago so I thought we are just returning the favour. [LA#3 009, female, relational, aged 79, proxy with user].

The potential conflict of interest between proxies and users was arguably greater among the three proxy respondents that were themselves employed as PAs or that employed close relatives – one of these proxies was the main family carer but employed the daughter as the PA. In all these cases the proxies had given up paid work to become the main carers of their relatives (and in at least two cases also the PAs). It was clear that the decision to abandon paid work to be the main carer had carried with it a significant personal sacrifice. This was arguably more evident in the case of a proxy respondent that had previously held a higher ranking position (and was the main family carer and employed her daughter as the PA):

Do I give up work and take over full time as a carer? Or do I put her in a home? And it was a very hard decision I have to say, it really was. I'd worked for 31 years as a civil servant. I worked for a local authority housing department. So you know, I'd been there 31 years and it was down to: do I give up my lifetime career or do I care for my mother-in-law [name omitted due to confidentiality]? And I just couldn't bring myself to put her into a home [LA#3 006, female, relational, aged 80, proxy without user].

In the above-quoted example, and in another case where the proxy was also the PA, money did not seem to have played a fundamental role in the decision to deploy the DP. The third proxy however, referred more explicitly to money as part of the motivation, albeit not the only one, for becoming the PA:

But there were a lot of different ones [agency carers] that sort of come in and she wasn't a lover of that. So I said, "Well I'll just..." 'cause I was sort of on the verge of

giving up work, getting towards retirement so I said, "Well I could sort of give up work and do that so they can pay me a bit of money for doing it," [laughs]. [LA#3 003, female, relational, aged 92, proxy with user].

This was also the only case among proxies that were also PAs, or acting as the main family carers, where the proxy also referred to issues of social status attached to the caring role (and to her own previous occupation). This could also have worked towards reinforcing the financial motivation for becoming the PA:

The family member..., yeah 'cause a lot of them won't do it. A lot of them don't want to know. I mean most of them have got husbands or have got a good job and want to carry on working, they don't want to do it. And a lot of people sort of don't like doing caring and cleaning, but I've been a cleaner all my life so I'm used to sort of getting on with it, sort of thing. Whereas some people have got a good job and they're in an office or whatever and they don't want to do that sort of work. [LA#3 003, female, relational, aged 92, proxy with user].

It was not possible however, to ascertain whether the actual users in these three cases would have had strong objections to their relatives being the PAs, or their main carers.

To summarise, in the initial decisions of users with dementia and their proxies, there is a strong motivation for remaining at home, which was not so apparent in other groups. Beyond this, there was also an element of relationship in the initial decisions that is salient to the objectives of this study. Users or their proxies craved for continuity of care and valued the establishment of a bond with the person delivering care – which is pertinent for the first hypothesis being explored by this study. The next section explores in greater detail the issue of relationships.

6.6.2 RELATIONAL ASPECTS OF CARE

The views of users with dementia or their proxies regarding the relational aspects of care were very much split along the same lines as the three groups of users defined before, i.e. purchaser, employer and relational-type users (see section 6.4). This was also evident when users or their proxy respondents talked about their relationship with paid carers, for example, with employer-type users (or their proxies) having somewhat closer relationships with their PAs than those that were purchasing care from agencies had with their agency carers. There was, however, one significant difference, which was the importance attached by all users with dementia or proxy respondents to continuity.

Continuity was an important aspect of how in general interviewed users valued care, as seen throughout the previous sections. More than ensuring knowledge of care needs (one argument in favour of continuity among other users), for those with dementia or their proxy respondents, the establishment of a rapport with a paid carer (whether a PA or agency carer) meant fundamentally that: i) the user would be able to recognise the paid carer and thus feel in familiar surroundings; ii) the paid carer would be able to interact with the user; and iii) the bond thus created would facilitate the provision of care.

Proxy respondents considered the first two points to be very important for the well-being of their relatives, namely as they were associated with contributing to improve, or at least maintain, their cognitive ability. This was obvious in the case of PAs who were also relatives. A similar degree of satisfaction could, however, also be experienced with PAs that were previously strangers after some time had elapsed and a relationship had been built:

I am fortunate in that she's not aggressive, she can be verbally aggressive but she's not violent or anything like that. And she is quite happy to sit in her chair and watch TV. She loves the grandchildren coming and going and that. Yeah, she is still getting stimulation, you know, because there are always sort of people in and out and the grandchildren. I've got a 16 year old and her friends come round, and they're really good, they sit and talk to my mother-in-law [name omitted due to confidentiality]. So she is still getting a lot... [LA#3 006, female, relational, aged 80, proxy without user].

On Sundays it's just the three of us [the nuclear family] and it feels really odd [chuckle], and my mother is always asking when is the carer [name omitted due to confidentiality] coming over, when is the carer [name omitted due to confidentiality] coming over. She loves it here. She's motheritchka [sic], the carer [name omitted due to confidentiality] is my mother and my father is her father and I'm her sister [laughs] [LA#3 013, female, employer, aged 86, proxy with user].

For proxy respondents, some of whom were co-residing with their dependent relatives, establishing a bond with a paid carer from outside the household was also important because care was taking place within their (proxy respondents') own homes. In at least one case the PA was living with the family. For these proxy respondents, the building of a relationship with the paid carer (whether PA or agency carer) was also linked to the establishment of trust in a context where their relatives were perceived as being particularly vulnerable due to

their condition, i.e. bonding with the paid carer could also be reassuring for the relatives of the person with dementia:

Because you know, we've got elderly, children... somebody coming in, I don't want a criminal record. I don't want to come in and see my mother-in-law [name omitted due to confidentiality] with bruises on her back and things like that. And so those are all my main concerns and they are what I would be looking for [LA#3 006, female, relational, aged 80, proxy without user].

Users with dementia arguably provided the best example of the salience of Baldock's (1997) concept of user as a co-producer of care. It was not uncommon for users with advanced stages of dementia to show challenging behaviour or resist receiving care. This made the rapport established with the paid carer fundamental to the provision of care taking place, i.e. for the user to at least consent on care being provided:

And there are all these... she has certain habits in terms of how to get food and we know all that and there are all these things that we are able to do that not all the carers would be able to do [LA#3 009, female, relational, aged 79, proxy with user].

While users - or their proxy respondents - purchasing care from agencies expressed their satisfaction with the agency carers they had, there were nonetheless reports of how being unable to choose the agency carers and to guarantee their continuity sometimes caused problems in delivering certain types of care. One proxy respondent that used agencies recalled that she had at least some added leeway on the choice of agency carers as she was able to rely on the manager of the agency to choose adequate carers. She also had some room of manoeuvre to change them if they did not suit her mother.

The ability to bond with the person delivering care was something that both users and their proxy respondents seemed to value. Recognising the paid carer was perceived as contributing to the user's wellbeing and satisfaction, as well as improving the perceived quality in the delivery of care. Establishing a rapport with the paid carer (whether PA or agency carer) was also important for proxy respondents to feel assured about the well-being of their relatives with dementia and to feel safe in their own homes.

A number of the excerpts and narratives presented in this section were voiced by proxies. There were, as discussed above, some specific themes that pertained to the condition of

dementia but others were more general to the condition of needing care. Regarding the latter, there was a striking similarity between many of the issues raised by proxies and how they were expressed, and those narrated in earlier sections by users themselves (i.e. those without dementia). For example, in the following excerpts, three different proxy respondents offered their views on the importance of continuity and the issues they highlighted, as well as the examples provided, are very similar to those offered by users without dementia (see section 6.4.1):

They are constantly talking, constantly engaging. They are finding out what my mother [name omitted due to confidentiality] wants, without us intervening, because obviously things change. Because one day they might need help with the food and the next week with something else. It depends on the needs rather than what's described as tasks. [LA#1 001, female, employer, aged 72, proxy with user].

You know, they just talk about generally things, you know, and I just think it gives that family feeling that they can make a cup of tea and they can... you know, it's just more than just someone coming in, shower, cup of tea, in the chair, gone. [LA#3 004, female, purchaser, aged 74, proxy with user].

Yeah. Someone like my mum she needs to have someone to help her get up, dress up and bath. You don't want someone that you don't feel comfortable with, do you? [LA#2 004, female, purchaser, aged 77, proxy with user].

As with the issues raised in the decision leading to the DP and how to use it (see section 6.6.1) there seems to be some coherence in many of the subjects that were voiced by proxies and other users of DPs without dementia.

There was one issue, however, that did not feature so prominently in the discourses of many proxies as it had in those of other older DP users. As mentioned earlier, many of the proxies were also the PAs, or at least the main family carer. Issues around boundaries between kinship and employment relationships or feelings of concern about overburdening relatives were much less frequently referred by proxies and particularly absent from the narratives of those that were themselves also the PAs or employing other relatives as PAs.

6.6.3 NEGOTIATING TASKS AND THEIR TIMING

An important issue alluded to before (see section 6.6.2) was timing of care. Users with dementia and their proxy respondents were very keen on being able to negotiate times, as well as have some flexibility to match care with the not always fixed care needs of their relatives. This was somewhat facilitated when users were employing relatives as their PAs. In those circumstances, it was relatively straightforward to provide care to the user or arrange for respite when a relative was the main carer:

And it is more flexible. If she wants to get up at nine, we get up at nine or early hours in the morning and once she is asleep, she's asleep. She tends to sleep a lot longer now than before [LA#3 009, female, relational, aged 79, proxy with user].

You know, if my mother-in-law [name omitted due to confidentiality] was going to day centre say on a Thursday and a Friday I might have an appointment on Wednesday or on Monday, so I'd then have to sort of juggle everything around. So at least now I can call in other people that I've got working for me if I want to go to the shops for a couple of hours or go and visit a friend. So it does give me a lot more control over what days and that [LA#3 006, female, relational, aged 80, proxy without user].

The definition of care schedules with PAs that were relatives (there were no PAs among users with dementia that were friends or neighbours) took place within familial relationships. Relatives employed as PAs tried to follow the user's preferences or needs in terms of the timing of care. Agencies were less able to provide this extreme flexibility, which prompted users and their family carers to adapt to their schedules. For example, one proxy respondent used agencies to cover the periods of time while she was out working or picking up her son from school.

Regarding the definition of tasks –*what* and *how* care was provided– this was very closely related with the ability of paid carers (whether PAs or agency carers) to be accepted by the user to deliver care. This was a key concern in the narratives of users with dementia and their proxies. One proxy respondent, for example, referred to having new agency carers “shadowing” the incumbent carer in order for them to learn how best to deliver care to her mother. Accepting care was arguably the issue that featured most prominently in the definition of tasks in the narratives of users with dementia and proxy respondents, particularly in the case of users with advanced stages of dementia.

Interviewees, however, expressed increased satisfaction with the added control that DPs provided them in defining care tasks in light of what they perceived as not always very clear or adequate care plans or assessment procedures by LA social services. The issue of respite care was already mentioned, i.e. being able to have respite care while maintaining the user at home, but there were other examples. Proxy respondents felt they could prioritise certain care tasks that had been overlooked or downplayed in the assessment procedure, which they felt were important to the user. Such tasks included socialising or receiving certain types of personal care, such as bathing, hairdressing or manicure. The importance of this in the context of dementia is best understood in light of the fact that this group of users (including their proxies) was also the one who voiced more complaints about their assessment of needs. The following excerpts illustrate some of the complaints and apparent difficulties faced by users and their relatives in the process of assessment of needs of people with dementia:

My mum, she told them she can do everything and that's the end of assessment. She doesn't need any help. And then there is us on our knees in the back trying to keep everything running smoothly. It's not a straightforward service at all, unless you know it [the process of getting DPs] [LA#3 012, female, purchaser, aged 81, proxy without user].

I mean, they didn't sort of exactly know what her needs were until they had the carers [from the LA] come in for them to sort of like say, "Well yeah, she's got to have somebody to cook her meals, she's got to be washed," you know, "Got to have somebody to put her to bed at night" and all that sort of thing. But they never considered, you know, the times when she would have to get up in the night, like if she wants to go to the loo in the night [LA#3 003, female, relational, aged 92, proxy with user].

It is important to point out that these difficulties in the assessment of needs of people with dementia did not reflect differences between LAs, but were common to all participating LAs.

As with the previous findings for purchaser, employer and relational-type users among the total sample, employing a PA seemed to convey increased leeway and flexibility in the definition of care tasks and times. There was, however, another strong finding emerging from the narratives of users with dementia and their proxies: that bonding with the paid carer (whether PA or agency carer) could greatly facilitate the acceptance of care by the user. This is of particular relevance to the second hypothesis under study, i.e. that the paid carer has an impact on the provision of care tasks. This was referred to by both purchasers of agency care

and those employing PAs, whether acquaintances or not. This provides a clear example of how relationships could contribute to enhance the role of users as co-producers (or at least willing facilitators) of care received.

6.6.4 SUMMARY OF THE MAIN ISSUES RELATED TO USERS WITH DEMENTIA

Users with dementia and their proxies made different choices as to the use of their DPs, but the analysis of their narratives afforded insights into some distinguishable features of the relational and co-production aspects of care in the context of dementia. These are summarised in the following points:

- The ability to recognise and relate to the paid carer played a much more crucial role in the delivery of care of people with dementia. Not only did it improve the experience of receiving care and the matching of how care was delivered with the user's preferences – similarly to what the other users (i.e. those without dementia) had expressed – but it greatly aided in securing the collaboration or consent of users with dementia to receive care.
- The establishment of a rapport with paid carers was also credited with reducing anxiety and improving the wellbeing of users with dementia. When familiar carers (not necessarily only those that were family members) engaged with the user, this was perceived as contributing to maintaining the user's sense of familiarity with the surrounding environment and maintaining the user's cognitive ability.
- Flexibility in the timing of care was of particular importance to users with dementia and this was facilitated when PAs were employed. The nature of the needs and condition of users with dementia meant that needs could not always be timed to the schedules of agencies. In these circumstances, live-in relatives or employed PAs could more easily and affordably deliver care when required by users.

One salient caveat concerning this section is that most of the analysis was based on the proxies' narratives and what they perceived as their relatives' (the DP users) experiences and wishes. One cannot rule out that some of the choices made or views expressed by proxies were actually reflecting their own preferences. It seemed, however, that the decisions regarding the deployment of the DPs were mostly driven by motivations of concern for the user rather than the own self-interest of proxy respondents. Similarly, some of the narratives of proxies on issues pertaining to the relational aspects of care were strikingly similar to those of other older DP users themselves without dementia. As far as the hypotheses under study are concerned, the findings for users with dementia and their proxies seem to provide

support for the proposition that relationships can be an integral outcome of care – first hypothesis – while at the same time contributing to the delivery of care that not only better fits the preferences of users, but also contributes to the acceptance of care delivery – the second hypothesis.

The analysis of the narratives of users with dementia and their proxies concludes the description of the findings of this study. Having gained a better and more detailed understanding of how the relational and the co-production nature of care impacted choices and the experience with care of older users of DPs in England, it is now possible to attempt to make sense of the findings in view of the initial research question and hypotheses. This is the subject of the next concluding section.

6.7 CONCLUSIONS

This study sought to explore how and why older DP users' experiences with care are impacted by the decision to hire a PA rather than to acquire services from an agency. It was conjectured that relationships are an important part of caring, based on an extensive literature review (see Chapter 2), and therefore choosing the identity of the paid carer would matter to the user (hypothesis 1). Moreover, the identity of the paid carer was also supposed to play a role in defining care tasks and times and through that, impact the perceived satisfaction with care, as the user is also a co-producer of care (hypothesis 2).

The findings presented in this chapter provide significant evidence of the importance of relationships in long-term care. The inability to establish a rapport with agency carers was among the loudest complaints of interviewees who in the past had received care from home care agencies under LA-managed care. All interviewees recognised the *instrumental value* of relationships, even those that were more detached, as they enabled the delivery of preferred care. Bonding with the paid carer (whether PA or agency carer) was thus fundamental to receiving personal care, particularly of a more intimate nature (e.g. bathing). Continuity also ensured that paid carers were familiarised with the user's preferences and changing needs. For users with dementia and their proxy respondents, establishing a rapport with the paid carer was deemed crucial to overcome possibly challenging or uncooperative behaviour in the delivery of care, and credited with improving the well-being of users.

Beyond the instrumental value of relationships stated above, some users also attached *intrinsic value* to relationships. As care was provided to older people in their homes who were often in a vulnerable situation, bonding with the paid carer was part of the process of

establishing trust when the paid carer was not an acquaintance. Building a bond with the paid carer was also very much linked to the concept of *home* for users. Finally, building a rapport with paid carers also allowed users to receive social support and companionship that many considered important in the context of dependency. It was clear that users derived great satisfaction from this relational aspect of care, and having control over the identity of the paid carer had thus been an important driving factor in the initial deployment choice of many users who opted for PAs.

Further evidence of the importance of the relational aspects of care was found in the way interviewed users defined their relationships with paid carers. Many relationships were built on reciprocal or symbolic gift exchanges – an issue that emerged from the narratives and that had not been totally evident in the literature surveyed. Many users defined their PAs as friends or family-like, even though users had initially not been acquainted with them. This was another salient finding: relationships could develop and become quite close once sufficient time had elapsed. Once trust had been established, users could go as far as relying on the PA's judgement to hire replacements.

Nevertheless, a significant minority of interviewees had opted to purchase care from agencies, which provided them with much less leeway over the identity of the paid carer. These interviewees reported wanting and having much more detached relationships, defining their rapport with agency carers as professional rather than a “fictive kin relationship” (Piercy 2000, p.365). Their relationships with agency carers had more strictly defined boundaries and reciprocal exchanges were mostly absent. Furthermore, their narratives suggest that they valued the relationships more for their instrumental value. These differences in relationships could partially be attributed to the more severe constraints that purchasers faced in the choice and interaction with agency carers. As mentioned earlier, they had less control over the choice and ultimately over maintaining agency carers. Agency rules in all likelihood gave them less leeway to give symbolic gifts to agency carers. Still, purchasers seemed equally satisfied with their more professional relationships with agency carers, and some actually sought to keep relationships at this more detached level. Some purchasers who had more long-tenured agency carers recognised that they had become closer with their carers, but without coming to define their relationship in the same way as most employer and relational-type users. There was therefore an apparent connection between the value attached to relationships and the initial deployment options of users, as those that valued relationships merely as an instrument opted for agency care. Furthermore, this clustering of

relationships seemed not to reflect differences in other characteristics of users, such as age, social networks or living arrangements.

Beyond the above-mentioned reciprocity, there were other issues that had not been totally foreseen in the literature reviewed in Chapter 2 and that came up as important in the narratives of users regarding relationships. Some of these unexpected issues provide some clues as to the differences found in the sample. Firstly, there was the issue of boundaries in relationships. Many users wanted to contain caring relationships and did not want them to evolve and eventually resemble fictional kinships. Secondly, purchaser, but also employer and some relational-type users (those who did not employ relatives or friends) expressed deep-rooted reservations about crossing the lines between employment relationships and friendship or kinship, even if this would have allowed them to circumvent the uncertainty inherent to the experience good nature of care as a relationship. Even when acquaintances were available, these users did not resort to employing them as their PAs. One can thus not rule out that older users simply have different preferences as to the nature of their relationship with those providing care to them, or as to the role of family and acquaintances in providing care.

Another relatively novel factor that seemed to influence interviewee's choices were the trade-offs involved in choosing between a PA and a home care agency. Purchasing care from agencies was often a less uncertain process, both in terms of available information, bureaucratic requirements and possibility to have backup in case the paid carer was unavailable, even if it entailed less possibilities to choose the identity of the carer. Purchasers came to express less anxiety in their choice process – and thus resembled relational-type users in this aspect – despite having much less leeway in the choice of carer.

Relationships in long-term care thus matter, but in different ways to different people. In one aspect however, the different types of users interviewed seemed to concur: relationships have at the very least an instrumental value in the delivery of care.

The empirical findings of this study seem to provide a stronger support to the second proposition of this thesis: that having greater leeway in choosing the identity of the paid carer would translate into greater scope to shape care to the needs and preferences of users. Users that had employed PAs enjoyed greater leeway to define times and care tasks. Regarding times, these users were able to receive care at very early or late hours and had greater scope to change times at short notice. This meant that they could better tailor care to their changing needs and fit care into their daily routines. This contributed to their satisfaction with care

received. Interviewees that employed PAs often reported receiving longer hours of care than they had been attributed with DPs. This flexibility of caring schedules was something that agencies did not match among the users interviewed.

Regarding the definition of care tasks, employing a PA provided arguably greater room for manoeuvre to receive a wider range of care tasks including less conventional forms of care, such as socializing, or tasks such as domestic help. However agency carers who provided care to the same user for some time were also willing to provide the latter. To some extent, this was made possible by the greater ability of users to *bank* hours when employing a PA.

It could be argued that these differences mostly reflect the constraints faced by home care agencies in the delivery of care, namely in terms of their human resource management. This argument notwithstanding, the findings support the view that being able to forge a bond with the person delivering care also impacted the definition of care tasks, and through this user, satisfaction with care. Interviewed users admitted to feeling more confident asking for changes, i.e. tailoring care to their needs and preferences, as they developed a bond with the paid carer. This was reportedly also the case with agency carers after some time had elapsed, i.e. after a rapport had indeed been built.

Continuity could greatly enhance the ability to receive tailored care also because it allowed paid carers (whether PAs or agency carers) to gain a very good understanding of how users preferred tasks to be carried out and knowledge over the user's changing needs and moods. The continuity also improved the experience of delivering personal care. The impact of continuity in the delivery of care was perhaps the most evident among users with dementia. Baldock's (1997) notion of the user as co-producer of care, built on the premise that delivery of care requires at the very least the passive consent of the user, was in full display in the narratives of these users or their proxy respondents. Bonding with the paid carers, and having a familiarity with them, was key for users with dementia to receive care and to their experience of care.

Having analysed the findings at length, a number of issues remain however. Thus far the findings have been summarised against the backdrop of the main research question of this thesis and its main propositions (see Chapter 4), but these findings have not yet been discussed in terms of how they might confirm, contradict or extend the literature reviewed earlier on this topic (see Chapters 2 and 3). There are a number of apparently novel issues raised by the findings regarding long-term care in England, chiefly the role played by reciprocity, which may merit a discussion of the findings through different lens, i.e. to link the

findings with other streams of literature. The findings presented here may also lend themselves to the discussion of new theoretical knowledge, or contribute to changes in policy practice. These same findings may also have caveats or limitations beyond the ones already mentioned (see Chapter 5) that are worth bearing in mind. All these important matters are the topic of the Chapter titled *Discussion* that follows.

Chapter 7 : DISCUSSION

Since its inception, this thesis has revolved around the issue of how older people make their choices regarding long-term care, in particular how the relational and co-production aspects of care affect the choices of older people and their experience of care. This has been discussed against the backdrop of user choice policies in long-term care, a policy area where theories based on rational choice have been dominant. The depiction of users as consumers of care, choosing between competing providers, has been challenged on the grounds that users of long-term care may deviate from rational consumers and that markets of care may be vulnerable to market failures or produce inequitable outcomes. By comparison, scarce empirical attention has been paid on how the relational aspects of caring impact decisions made by users (see Chapters 2 and 3). The empirical analysis of this thesis has been carried out in the context of user choice in long-term care in England, in particular among older users of Personal Budgets (PBs) that have taken-up the benefit as a Direct Payment (DP) of cash that can be used to employ their own personal assistant (PA) or purchase care from home care agencies. The main research question that this thesis sought to answer empirically was how and why users' experiences of care are affected by choosing to hire a personal carer rather than to acquire services from a formal provider.

To this end, this thesis has employed qualitative methods of data collection and analysis, namely Framework Analysis (Ritchie & Lewis 2003), to explore how choices and experiences with care may be impacted by the relational components of care, using a sample of older users of DPs in three LAs in the greater London area (see Chapter 5). This methodology allowed older DP users to be probed on their decisions and experience of care and for a better understanding of the subtly constructed nature of relationships. The different possibilities for deployment of DPs, i.e. purchasing care from home care agencies, employing a professional PA or employing an acquaintance or relative as a PA, have been used as a typology of users to further explore differences and similarities in their narratives.

The previous chapter has presented the findings of the analysis of narratives of interviewees. These findings focused on the context leading to the choice of DPs and its deployment – i.e. the initial choice between purchasing care from home care agencies and employing a PA – and the role played by the experience good nature of care (both in terms of its relational and co-production components). It also looked at how interviewees valued relationships and how relationships with paid carers were defined and constructed over time; how tasks were defined; and finally how all these issues impacted care provided to people with dementia. The

narratives of users and their proxies were also analysed in terms of the similarities and differences between the three groups of older DP users described above: purchasers of care from agencies, employers of PAs that were previously unacquainted to users, and the denominated “relational” users who employed acquaintances (e.g. relatives or former paid carers) as their PAs.

This chapter aims to place the empirical findings in a broader picture. This means comparing the results of this thesis against other findings from empirical studies, and seeing how and why the results of this thesis might confirm or challenge pre-existing knowledge, namely that surveyed in Chapter 3. It also means advancing the theoretical knowledge by discussing the findings in light of the existing theories reviewed in Chapter 2, and how the findings confirm or dispute them. Beyond the theoretical implications, this chapter will also aim to establish the salience of the findings in terms of its policy implications in the context of user choice policies in long-term care in England. Finally, this chapter will also critically examine the possible limitations of this study, and how they might impact findings; it will also discuss possibilities for additional research.

This chapter is organised as follows. The first section summarises the findings of the previous chapter on which the discussion will be based. The second section discusses these same findings in light of previous theoretical and empirical studies and around three main themes, each constituting a sub-section of its own: the importance of the relational aspects of care; the role of reciprocity; and the compatibility of the findings with the theoretical paradigm of rational choice. The first sub-section discusses the importance of the relational aspects of caring through the lens of its intrinsic value, i.e. the satisfaction that is directly linked with the feelings of concern from the paid carer. It also looks at its instrumental value, i.e. how the rapport with the paid carer allows users to receive more and better care. The second sub-section debates and expands on the role of reciprocity in caring, for example, in light of Collopy’s (1995) discussion over decisional autonomy; the disability critique on the ability to reciprocate; and the literature on the role of norms and values in choice (cf. England & Folbre 2003; Roth 2007). The last of these sub-sections discusses findings in light of rational choice theories that underpin many of the user choice policies in long-term care in England, i.e. to what extent the behaviours depicted in this study are in line with the rational choice tenets. The third section of this chapter attempts to draw some possible policy implications from the findings. The fourth section depicts the limitations of this study and discusses ideas for further research. Finally, section five sets forth the main points of this thesis as concluding remarks.

7.1 SUMMARY OF FINDINGS

Arguably one of the starker contrasts found among the narratives of the interviewees was the role played by the relational aspect of care in the choices made by older users of DPs. Those that ended up purchasing care from home care agencies had attached much less emphasis on the relational component of care. They were, for example, less adamant about choosing the identity of their paid carers. In contrast, the initial choices of many among those that had employed a PA reflected much more the relational aspects of care. Indeed their choice of deployment of DP resulted to some extent from their preferences for a closer rapport with their paid carer, which was not apparent among those purchasing care from agencies. When making their initial choices, some already had a particular person in mind to become the paid carer. Others wanted to have command over the choice of the paid carer in order to receive companionship, and others still sought to ensure greater continuity of care. Besides these more relational factors, many interviewees resorted to employing PAs because of what they perceived as a greater ability to get more tailored tasks, sometimes following the refusal by home care agencies to deliver some types of care.

What is also clear is that the initial choices over deployment of the DPs involved trade-offs. In essence, the purchaser-type users were often consciously trading away flexibility and choice over the identity of the paid carer (something both relational and employer-type users had) for added reliability, reduced uncertainty and less managerial responsibilities. For those employing PAs, the psychological costs of the process of choosing could be significant, particularly when the PA was not an acquaintance. The main psychological cost was increased anxiety over the paid carer's trustworthiness – a clear example of the experience good nature of care. Like employer-type users, purchasers also did not know their paid (agency) carers in advance and were therefore also faced with uncertainty. However, purchaser-type users came to resemble relational rather than employer-type users in experiencing less anxiety in the choice of carers, albeit through different mechanisms. Relational users obviously knew their PAs beforehand while purchasers devolved the decision regarding paid carers to agencies.

One obvious way to deal with this anxiety would have been to employ a friend or relative whom users already knew and trusted. In this respect, the narratives of most employer-type interviewees overlapped with those of purchasers as both expressed serious reservations about managing employment relationships in the context of friendship or kinship, as well as concerns about burdening their acquaintances. This was another example of how the

relational aspects of care could shape initial decisions: keeping relationships of a different nature separate.

In essence, the relational aspects of care divided purchaser-type users from those employing PAs (despite overlaps in some issues discussed above) and this carried on to how interviewees of different types defined their subsequent relationships with paid carers. There was a wide variety of relationships established between DP users and their paid carers. These ranged from relationships that were defined on relatively strict professional terms and with clear set boundaries, to sometimes very close relationships that had either carried over from pre-existing relationships, for example, when a neighbour was employed as a PA, or had been established in the course of the provision of care. Some of the relationships built with paid carers were defined as akin to family relations. While close relationships could be built over time with PAs that were initially strangers, a number of interviewees kept a deliberate distance with their paid carers, i.e. they deliberately sought to contain their rapport with them. These interviewees were mostly of the purchaser-type. This distance could be felt in the nature of their conversations, or the times during which these interviewees considered appropriate to interact with their paid carers. Another important finding was thus that not all users preferred to develop close relationships with the person delivering care to them. The detail of interviewees' narratives allowed for the systematic exploration of possible links between different relationships and some of the users' characteristics. For example, users living alone or with limited social networks might have had closer relationships with their carers as a way to compensate for lack of social contacts. This was, however, not the case. Regarding time – i.e. tenure of the paid carer and/or frequency of contacts – it was clear that relationships with paid carers that were initially strangers required time to develop. Time was not sufficient, however, for family-like relationships to develop. Most purchasers had long-tenured agency carers and still reported relatively more detached relationships.

One relatively unexpected finding that arose from the narratives was the presence of reciprocity and its role in defining relationships. The relationships defined around friendship and “fictive kinship” (Piercy 2000, p.365) almost always involved a reciprocal element. The resources exchanged encompassed not only material exchanges such as the occasional gift of a paid meal, but also time and social support. Two elements defined the boundaries of reciprocity: firstly, with one notable exception, the gift exchanges were of limited monetary value; and secondly, they were not monetised, i.e. they did not involve cash. Reciprocity was mostly absent from the more professionally-defined relationships that purchasers-type users

had with their paid carers, although this could also relate to constraints posed by home care agencies regarding the acceptance of gifts by their paid carers.

Regarding the first of the two hypotheses that were set up in the beginning of the research – i.e. that employing a PA could entail higher user satisfaction than contracting a formal service provider, by allowing the user to choose from whom to receive care, which would matter to the user given the relational nature of long-term care – the conclusions are somewhat mixed. Those employing PAs did tend to have deeper relationships with their paid carers, whom they had been able to choose, and this rapport clearly contributed to their satisfaction with care. For some among these users, the choice of deployment of DPs seemed to reflect their preference for these closer relationships. In contrast, those purchasing care from agencies did not have such close relationships, nor did they have the same leeway in choosing their paid carers with the agencies. This may reflect preferences for more detached relationships – after all these issues were almost absent from their narratives concerning the initial choice of deployment of DP – as well as their lesser latitude to build relationships, both because the continuity of agency carers depends ultimately on the home care agencies that employ them; and because they had a more limited scope to reciprocate. Differences in time spent with the carers or living arrangements did not seem to explain differences between users. Purchasers were not, however, less satisfied because of the greater detachment of their relationships with agency carers. Their more detached relationship, as well as the absence of responsibility they had traded off, seemed to suit their preferences. Overall, the relationships established with paid carers seemed to correspond to whatever the users had wanted this relationship to be, i.e. there was control over the relational aspect of care. This is one salient finding in the context of user choice policies in long-term care.

As for the definition and negotiation of tasks, it was clear that users appreciated having command not only over what care they received, but also how it was provided to them. In this respect, users that employed PAs had greater latitude to define what care to receive (e.g. by “banking” hours to be used for socialising and heavier household chores), how to receive it and especially when. The definition of care schedules with PAs could entail very early or late hours, as well as more flexibility as to the duration of the care received than what home care agencies could provide. However, some purchasers recognised that they felt more comfortable asking carers to perform different care tasks once some time had elapsed in their relationship.

While directly employing a PA seemed to confer greater leeway in the definition of tasks in the broader sense, there were other ways in which relationships – even detached ones –

could influence the process of care delivery. Firstly, establishing a relationship with the paid carer greatly improved the experience of receiving personal care. Secondly, as users familiarised themselves with their paid carers, they felt more confident to tailor care to their needs and preferences. Finally, the specification of how care should be provided was greatly aided by the continuity of paid carers, regardless of these being employed by home care agencies or users directly, as this afforded paid carers a knowledge of the user's often changing needs, moods and preferences. The knowledge of needs and preferences was particularly important in reference to Baldock's (1997) definition of the user as a co-producer of care. This interplay between continuity and the user as co-producer of care was arguably best exemplified by the case of users with dementia. The establishment of a rapport with the paid carer was deemed essential to the user to accept or at least passively collaborate in the provision of care, while also being perceived by proxy respondents as beneficial to their wellbeing. This also applied to proxy respondents who purchased care from agencies.

The findings thus seemed to point towards a more firm positive reply to the second hypothesis, i.e. that directly employing a PA granted users greater leeway in defining what care they received, how they received it and when. The findings indicate, however, that users also derive satisfaction from how care is provided by creating a bond with paid carers, as in the case of personal care. In other words, relationships could also contribute to the quality of care.

7.2. DISCUSSION OF FINDINGS

This thesis started out by critically discussing the complex and also disputed concept of caring, which despite featuring prominently in a wide body of literature has arguably only had limited take-up in the discussion around user choice policies in long-term care. As detailed in Chapter 2, the concept of caring is very much built around the relationship between the carer and the person cared for, which implies that long-term care is not just about performing tasks but also about creating a bond. At the same time, one of the strongest arguments around user choice is that it improves the outcomes for users, namely by better matching their needs and preferences with the care that is delivered (Le Grand 2007). If relationships are salient to the choices and satisfaction of users, for example, as an outcome of care, it is perhaps important to consider how they fit with user choice.

This section builds on these two streams of literature, caring as relationships and user choice anchored on rational choice, and draws on some of the concepts debated in greater detail in

Chapter 2 to discuss the findings of the research summarised in the previous section. This discussion begins with the value of relationships.

7.2.1 THE INTRINSIC AND INSTRUMENTAL VALUE OF RELATIONSHIPS IN CARING

The narratives analysed in the previous findings chapter were clear about the importance of establishing a rapport with paid carers, although these relationships could have different degrees of closeness. Being thoughtful and caring was in general connected by most users or their proxy respondents as an essential component of the quality of care they experienced. In a context of loss or diminishing physical independence, close paid carers could also provide valuable psychological support to older people. Familiarity with the paid carer was also fundamental for users to feel “at home” and for them to trust the carer. One example was provided by a couple of users who had opted to employ PAs; the relationship established with the carer was even more important as an outcome of care, as it allowed them to experience the sense of companionship and social connectedness that they sought.

These findings are in line with other studies, which highlighted the relevance for older people to choose the identity of the carer (Smith et al. 1995; Hardy et al. 1999); or where the relationships established with paid carers or the carers’ personal characteristics were equated with the quality of care received (Eustis & Fischer 1991; Edebalk et al. 1995; Piercy 2000; Olsson & Ingvad 2001; Lewinter 2003).³⁴ Similarly to the findings reported in this thesis, the rapport established with paid carers in these studies was also often characterised by users as one based on friendship or family-like, leading Piercy (2000, p.365) to coin some of these more intimate relationships with paid carers as “fictive kin relationships”. The narratives of users seem thus to vindicate Himmelweit (1999), Folbre and Nelson (2000) and Jochimsen’s (2003) arguments that good quality care is dependent on the carer showing a sincere concern for the user’s wellbeing. Therefore, the choice of *who* matters for the user’s satisfaction. Caring thus seems to carry with it an element of “emotional labour” (Hochschild 1983; cited by Himmelweit 1999, p.34), i.e. of management of personal relationships. In this context, continuity becomes an important factor for these relationships to develop and carry on with time.

³⁴ The issue of relationships is also addressed in other studies focusing on care home residents (Eales et al. 2001; Nolan et al. 2006; Wilson et al. 2009), but the issue is somewhat different in residential care as users are not the direct employers of their paid carers and have limited scope for changing them – even in comparison with home care users purchasing care from home care agencies – and users are not living in their own living environment.

From these findings and arguments, one possible conclusion is that relationships can be viewed as an outcome of care, one that is valued and sought by some users, i.e. for some users relationships have an intrinsic value in the context of long-term care. The satisfaction of users with the care received is thus connected to the ability to develop this rapport with paid carers and to the quality of the relationships established. Going back to the concept of caring reviewed earlier (Chapter 2), the intrinsic value of relationships fits with the views of the literature on the ethics of care, which stated that care is not only “caring for” but “caring about” (Graham 1983; Tronto 1993). It also fits with Folbre and Nelson’s (2000) arguments that feeling emotionally connected is an outcome of care in itself for the user. Besides the intrinsically human need to establish relationships, Carstensen’s (1995; 1999) “socio-emotional selectivity theory” provides a clue as to why relationships might be especially important for older people. Carstensen argues that as people age, they increasingly prefer to maintain fewer but more positive and emotionally satisfying social contacts. In other words, older people trade novelty and emotional variance in favour of maintaining fewer but more emotionally satisfying relations. This seems to apply also to long-term care settings.

This would be in line with the view that satisfaction depends on the subjective values of the user; therefore the perceived quality of social relations is likely to be different from user to user (Baldock 1997).

The intrinsic value of relationships in caring reinforces Baldock’s (1997) argument regarding the user as co-producer of care, not in relation to the tasks but to the emotional bond. As satisfaction with the relationship depends on the subjective values of the user, the perceived quality of caring relations is therefore likely to be idiosyncratic to each user. The intrinsic value of relationships thus reinforces the experience good nature of long-term care.

The findings of this thesis support yet another supplementary vision of the importance of relationships in long-term care: relationships also have an instrumental value. In an obvious analogy with the instrumental value of choice (Bartlett & Le Grand 1993; Dowding & John 2009), relationships can also be a means to obtain more or better care. First of all, the rapport established with the paid carer could greatly improve the experience of receiving personal care, even a more distanced rapport such as that depicted by purchaser-type users.

Secondly, establishing a relationship with paid carers was instrumental in allowing users to receive more care than they had been assessed, or to ask paid carers to carry out tasks beyond their care plan. Admittedly, the former was only possible for those employing PAs,

but the latter was reported even by those receiving care from agencies and those who benefited from some continuity of agency carers. To some extent, these findings mimic those found by Leece (2010) within a sample comprised mostly of disabled people of working age. In her study, DP users had also developed much closer relationships with their paid carers than those on LA-managed care. The employer-employee relationship of the former enabled them to exercise greater choice on what and how care was provided. Crucially however, her study reported findings before the implementation of the PBs, mostly for users of working age, and depicted DP users against those receiving LA-managed care that faced far greater constraints in their dealings with agencies than the purchaser-type older DP users of this study. Besides Leece's study, previous research had already associated DPs with the ability to tailor care and to receive less-orthodox care and higher user satisfaction (cf. Hatton & Waters 2011). This thesis, however, contributes to a better understanding of the mechanisms that allow older DP users to tailor care to their needs by unveiling the processes through which that is possible, namely by establishing a rapport with paid carers.

Finally, establishing a routine, or re-gaining a sense of normality in their lives, was an important aspect in receiving care among the users interviewed, particularly in light of often changing needs and psychological moods. The rapport established with paid carers allowed the latter to know the needs, moods and preferences – i.e. how to deliver care – of users. The instrumental value of relationships was very much on display for people with dementia, who more often reacted positively to receiving care from paid carers they knew and related to.

The instrumental value of care, particularly in the case of people with dementia, refers back to Baldock's (1997) concept of the user as co-producer of care, but this time in relation to the care tasks. Baldock's concept highlighted the idiosyncratic needs of users and how the delivery of care requires at the very least the passive acceptance of care by the user. This thesis provides some evidence that the relational aspects of care facilitate this acceptance in the case of people with dementia, and allow for the idiosyncratic needs, and indeed preferences of users, to be met. The latter, allowing for idiosyncratic needs and preferences to be met, was true also for sampled users without dementia. The extent to which the instrumental value of relationships configures simply a manifestation of self-interested behaviour by users is hard to pinpoint exactly, given the elements of reciprocity that characterise many of the bonds established between users and paid carers.

7.2.2 RECIPROCITY IN THE CONTEXT OF DEPENDENCY

Reciprocity was arguably one of the strongest themes arising from the narratives of users in this study. It clearly played a role not only in the satisfaction of users, but crucially also in the definition of relationships. As it was clear in Chapter 6, the presence of reciprocity was one of the defining characteristics of deeper, i.e. beyond professional, relationships.

In the literature on caring (see Chapter 2), authors such as Himmelweit (1999) and Jochimsen (2003) defined the relational nature of caring as one often built around asymmetric relationships because of the user's limited ability to reciprocate. This, they argued, could constitute a strong moral obligation to care for someone. Although Jochimsen (2003, p.39) referred to the existence of gifts, these were defined as "sustained one-way transfers – without assuming even an implicit or deferred exchange pattern" in the context of care-giving for altruistic motives. Authors such as Fine and Glendinning (2005), and more recently Kröger (2009), have criticised this view of users as unable to reciprocate, by highlighting that older users of care are often also carers themselves, for example, when caring for grandchildren. The findings of this thesis seem to concur with Fine and Glendinning's critique and take it one step further. The reciprocal relationships described by users in this study were not confined to grandparenting or intergenerational transfers to their next of kin. They extended to paid carers that were previously not acquaintances, and included forms of reciprocity based on social support, exchanges of time, or symbolic gifts. In other words, this thesis demonstrates that reciprocity is not only possible, but very much present in caring relationships taking place outside familial relationships. In this sense, the findings of this thesis provide support to a view of caring constructed around interdependence and balancing of interests between the carer and the person cared for (Kröger 2009, p.409; Fine 2007). Clear examples of this are the accounts of reciprocity involving the timing of care between users and PAs.

What is novel about the accounts of reciprocity present in this thesis, is that the majority took place in the context of employment relationships. Going back to the arguments revised in Chapter 2, Kittay (1999; as cited by Fine 2007, p.68ff) had defined caring around power asymmetries. In the context of DPs, users may be dependent on carers, for example, for their physical needs, but they also hold a power position as employers, particularly those using PAs. There is therefore already an exchange taking place between users and paid carers, where care is provided in exchange for wages. Nonetheless, users and PAs apparently chose to engage in reciprocal exchanges beyond the ones framed by employment of paid carers. In her study of relationships in the context of long-term care in Denmark, Lewinter reviews

some of the literature on reciprocity that provides clues on why reciprocity plays such an important role in caring. Of particular relevance are the arguments presented by Caplow (1982) and Gibson (1985).

Caplow (1982) studied ritualised gift exchanges, i.e. gifts whose symbolic significance does not reflect its monetary value, which are similar to the exchange of social support described by some users in our sample. He concludes that those exchanges were fundamental to cement relationships that were valuable but potentially uncertain. The parallel with the dyad user-carer is evident. Reciprocity can create ties that bind in a context where the relationship is valued, but where the user is at the same time well aware that the paid carer may choose to leave at any time. One can argue that the paid carer is equally faced with uncertainty (i.e. the paid carer may be dismissed by the user), which further reinforces the scope for reciprocal exchanges to take place beyond monetary payments. Caplow studied the ritualised exchanges in familial contexts, but here too is another parallel with the findings of this study: reciprocity took place when relationships with the paid carer were defined on a level of friendship or fictive kinship.

Gibson (1985, p.49) equates reciprocity with independence for older people. Her argument is that dependency is seen as undesirable firstly because “it violates the ‘norm of reciprocity’”, i.e. the moral obligation to reciprocate that is present in social exchanges. Secondly, because it leads to a lack of “control over the form and content of the exchange itself” (Gibson 1985, p.50), i.e. the dependent person needs the exchange to take place (e.g. receiving care) and therefore has limited power to set the terms on which this exchange takes place. Being able to reciprocate, means that the user of care has greater opportunity to contribute to setting the terms in which the exchange, namely the timing of the provision of care, takes place and this may thus contribute to enhance his/her independence.

In the context of the findings of this thesis, reciprocity was also interesting for its absence. A significant portion of interviewees made little or no reference to reciprocal exchanges attached to care. What is more, the absence of reciprocity happened only when care was provided by agency carers and defined on a professional basis. Admittedly, the findings only allow for hypotheses about why this happened rather than certainties.

One hypothesis is that the purchaser-type users might simply have strong preferences for “keeping it professional”. There were some accounts of users that definitely did not want to be saddled with the carers’ “moans”. Another possibility is that the reduced leeway afforded in choosing the identity of the carer when purchasing care from agencies made it somewhat

redundant to establish reciprocal relationships. Among purchasers, the terms of the exchange were often set with the home care agency rather than the carer, and it was the agency that employed the paid carer. Going back to Caplow's (1982) arguments above, the ritualised gift exchange was probably rendered meaningless in maintaining a relationship that ultimately depended on the agency rather than the worker. Yet another hypothesis is that the possibility to engage in reciprocal ritualised exchanges with paid carers is more limited when purchasing care from agencies. According to LA staff interviewed, agency carers are often forbidden to accept gifts from users³⁵; exchanges involving time are rendered very difficult or impossible when the home care agency manages the carer's time. Although exchanges around social support would seem to face fewer obstacles, even these exchanges were absent.

Differences in reciprocity and the nature of relationships could also stem from other factors referred in the literature as affecting the nature of relationships established with carers (Eustis & Fischer 1991; Piercy 2000). Among these are the length of the relationship with the paid carer, the intensity of care or absence of other close relationships on the part of the user where close rapports with paid carers would compensate or replace the absent kinships. On the one hand, PAs did seem to provide more intense care than agency workers. This is partly because they often worked beyond their allocated times, and this could have helped reinforce their ties with users as well as the latter's sense of dependence and need to reciprocate with "goodwill" gifts. On the other hand, practically all interviewed users had been receiving care from their current carers (PAs or agency carers) for some months, which indicates that it is unlikely that the lack of reciprocity towards agency carers reflected "less tenured" relationships. Caring taking part within pre-existing familial relationships was evidently different as the kinship relationship predated the caring one. Similarly, some of the reported closest relationships with paid carers co-existed alongside reported frequent visits from relatives (e.g. children) or those co-residing with spouses. This indicates the limited substitution effect of caring relationships for absent kinship in this study.

The flipside to reciprocity is that it also creates moral obligations, as Lewinter (2003) and others correctly pointed out (England 2005; Folbre 2008). The issue of relationships in this thesis has been approached from the perspective of older users of care, since paid carers were not interviewed. It is thus possible that for paid carers, reciprocity may have a much

³⁵ Tipping agency staff could be viewed as a proxy ritualised gift exchange between users and agency carers with longer standing relationships, but there were no references in the narratives of purchasers to tipping.

more ambivalent meaning, i.e. it might contribute to their job satisfaction and alleviate their sense of alienation, but it may also leave them open to being exploited. Some of the more flexible arrangements described by users in this study could also have a detrimental effect on the wellbeing of paid carers.

7.2.3 RELATIONSHIPS, CHOICE AND MARKETS

The introduction of user choice and the underpinning marketisation of long-term care have been clothed in a discourse whose underlying basis is rational choice theory. It broadly depicts users as autonomous, fully informed consumers, entering and exiting liaisons with providers (see Chapter 2). In light of the preceding discussion about the role of relationships and reciprocal exchanges, how compatible are these findings with rational choice tenets? Or perhaps more appropriately, how do the findings advance the discussion around choice and competition in long-term care?

Before discussing the findings from the viewpoint of choice and competition, it is worth highlighting that the sampling procedure used in this study purposely selected older users of DPs (see Chapter 5). The interviewees could thus be considered as the most consumer-like among older users receiving publicly funded care. Because of this, the views expressed by these older users may not apply to other groups of older users, particularly those receiving LA-managed care (cf. Baxter et al. 2013 for a discussion on the experiences of the latter).

Bearing the above stated caveat in mind, the older users who were interviewed did, to some extent, exhibit consumer-like behaviour with their use of DPs. The majority of them had come to DPs after previous experiences with care provided by home care agencies (LA-managed care or privately funded); while recollecting these experiences, they described how they had eventually changed agencies when unhappy. Their current care arrangements had also often resulted from a process, where other carers or agencies had been used before interviewees settled with their current option. There was therefore evidence of using exit to bring about an improvement in the interviewees' care, akin to Le Grand's (2007) arguments about choice.

One often quoted reservation about the appropriateness of the concept of choice in the long-term care sector is the risk for endogenous preferences to arise from relationships with carers (Taylor-Gooby 1998; England & Folbre 2003; England 2005). As mentioned earlier, it was clear that the relational aspects of care often impacted the choices made by users and the wish to maintain successful relationships led users to engage in reciprocal symbolic exchanges with paid carers. It was not obvious, however, that relationships created such

strong obligations towards the paid carer so as to act as a barrier to exit. Relationships were “sticky”, i.e. it could take some time for users to change paid carers or home care agencies, as it took some time for users to build and assess their rapport with the carer or negotiate care. Despite this, relationships did eventually end if parties were not satisfied. This is compatible with what is observed with other experience good commodities, of which labour and probation periods in employment contracts are perhaps suitable examples.

Nonetheless, the findings of this thesis also raise important questions as to limits of conceptualising older DP users as consumers of care along the lines of rational choice theory. These limitations pertain to the existence of imperfect information, and the impact on choice of the psychological costs of choosing, including the costs of regret.

Interviewees expressed having *imperfect information* regarding prospective paid carers, especially when searching for PAs. This asymmetry refers to a gap in the care market pertaining to PAs, as discussed in section 7.3 below, namely as to the lack of regulation of this activity. Although this gap is one that could be addressed within the envelope of user choice policies (e.g. through a registry or accreditation of PAs), it could still have potential adverse consequences in terms of equity. Imperfect information tends to affect disproportionately those that are alone or less well off (Greve 2009). A source of imperfect information that is arguably more difficult to address is related to the relational component of care that the findings demonstrated to be an important dimension of care. Users had for the most part little information about how their relationship with a given carer would develop. It was not clear how this could be addressed (apart from rare cases where users had been able to “shadow” their future carers while they cared for other older people). At the same time, however, since human relations are an outcome of care, this places users in a more favourable position to judge quality of care (or at least the dimension of quality pertaining to relationships) *vis-à-vis* professionals (Greener 2007).

Although exerting choice over the identity of the paid carer was highly valued, it was clear that this was a process laden with anxiety; choice entailed *psychological costs* for older users of care. The narratives of interviewees presented several examples of deferred to or delegated decisions that are compatible with the existence of high costs of regret, for example, when they deferred to social workers regarding the choice of home care agencies (Thaler 1980; Beresford & Sloper 2008). Although this study does not present a counterfactual of the process of choice experienced by other older users (e.g. those on LA-managed care), these psychological costs may be a strong barrier to exerting choice (Dowding & John 2009). They might also have a significant impact on the choices made by

older people, as shown by Baxter and Glendinning (2013). Beyond these examples of delegated choice, there was also the case of people with dementia. In this case, relatives had often been the ones making most of the decisions on behalf of users – which could be considered a clear sign of limited consumer sovereignty (Eika 2009). These examples of deferred to decision-making may put into question the view of users as autonomous consumers of care.

Finally, there were a different set of constraints impacting users' choices and experiences of care. These pertain to social norms on whom to employ, and on the nature of the tasks involved in caring (England & Folbre 2003). In this context, the findings described in Chapter 6 provided evidence of the nuanced role that different types of relationships could have on choice. Friendship and familial relationships involved a different set of rules of engagement that were not always seen as compatible with the cash nexus of paying for care, which in turn led some users to dismiss the option of paying friends or relatives. This reflects a decades old-discussion as to whether commodification alters the fundamental characteristics of a service (Titmuss 1970) or not (Arrow 1972). It was clear that for many of the users interviewed, cash could potentially change the altruistic nature of care provided in the context of friendships and turn it into a service. Some tasks, particularly intimate care, also proved to be value-laden concepts. Relationships could be an enabling factor to receive personal care of an intimate nature, but at the same time close relatives did not always feel comfortable providing this kind of care. Finally, reciprocal symbolic exchanges described above are perhaps the best example of the role played by moral-laden concepts of choice within long-term care. What all these examples point to, is that caring is a morally contested commodity (Titmuss 1970; Granovetter 1985; Roth 2007; Sandel 2012; Besley 2013). This is an issue that remains relatively unaddressed in the discussion around choice and competition in long-term care.

Understanding care as a morally contested commodity allows for the above-discussed issue of reciprocity in caring relationships to be viewed through different lenses. It was previously argued that reciprocity in the form of gift exchanges could help to cement relationships (Mauss 1954 quoted in; Akerlof 1982, p.449; Caplow 1982). In this sense, these gift exchanges could be akin to an emotional efficiency wage, paid to reduce turnover and ensure continuity, which users clearly preferred. In labour economics, the concept of efficiency wages usually refers to situations where employers pay workers above their market-rate wage in order to enhance productivity, reduce shirking or reduce turnover (Akerlof 1982). Akerlof (1982) argued that firms may seek to raise productivity by providing a gift of extra

wages that increases the workers' effort by appealing to their sense of fairness, i.e. by operating through social norms rather than just monetary incentives. This would lead workers to reciprocate in kind by working more. The gift exchanges found in this study between users and PAs could thus play a similar role: reduce shirking, improve productivity (e.g. leading carers to provide more care than what they were paid for), and enhance continuity. As mentioned earlier, reciprocity would thus make more sense when employing PAs. There are two reasons for this: not only because the user is then clearly the employer, but also because the continuity (i.e. turnover) of agency carers ultimately rests on the home care agency and the carers, and not so much on the user.

In the above example of Akerlof's (1982) gift as wages, there is reciprocity – workers respond in-kind by raising their effort – but the gift exchange is still partially monetised. Reciprocity in caring relationships, however, was defined as a non-monetised gift exchange whose value exceeded its monetary charge. This is arguably a non-trivial nuance. It was clear in this study that users wanted carers not only to *care for* them, but also to *care about* them, particularly when employing PAs, where reciprocal ties were stronger. Emotional care or attachment was in itself an outcome of care sought by users engaging in reciprocal exchanges. It is in this context that the morally contested nature of care becomes important. Roth (2007) has pointed out that some exchanges, which are deemed repulsive when cash is used, lose their repugnant character when they take place as gifts or in-kind exchanges. He quotes the example of organ donations. In this sense, reciprocity could be akin to an *emotional efficiency wage* paid to ensure not only the carers' commitment or continuity, but also their emotional engagement. If one cannot buy with cash love and a sense of caring – both contested commodities from an economic point of view (Held 2002) – and if one wants them to be genuine and motivated by intrinsic motivations (Frey 1998), reciprocity may thus be the type of in-kind exchange that must take place in order not to crowd-out these intrinsic motivations. Evidently, the reciprocity bonds were analysed from the viewpoint of older DP users in the context of this study. For carers, these reciprocal exchanges could well represent a strong moral link that could render them "prisoners of love" (Folbre 2008).

7.3 POLICY IMPLICATIONS DERIVED FROM THE FINDINGS

Reflecting the disability rights groups' agenda of greater control and empowerment, the merits of user choice, and particularly DPs, have often been equated with the ability to employ one's carer (Stainton & Boyce 2004; Needham 2011; Moran et al. 2013). Arguably, one of the strongest policy implications of this study is that DPs have the potential to enhance the outcomes for older people, not only because they allow them to hire their own PAs, but

also because they allow for a better matching of people with different preferences regarding care. This is particularly salient in view of the nuanced findings regarding the importance of relationships. It was clearly far from evident that older users all wanted to have PAs, even among those with previous unsatisfactory experiences with agencies. Not all users want their care delivered in the same way, but equally, not all want the same type of relationships with their paid carers; DPs could apparently deliver both.

The rational choice thinking that partially underlines user choice policies for long-term care in England is clear about the necessity to have information for markets to function properly, particularly when there is mounting evidence of the experience good nature of care. In this respect, however, this thesis identified a gap in terms of the information available to older users of DPs that was particularly evident for those seeking to hire a PA. Despite the regulated nature of the DPs in England, the market for PAs still remains mostly unregulated. This is affecting older people's ability to choose and their experience with choice, for example, by contributing to the anxiety surrounding the process. At the time of the study, only a system of voluntary registration had been enacted by the *2012 Health and Social Care Act*. This is clearly an area where LAs could invest, namely by setting up directories of PAs with checks about their experience and safeguards. One of the participating LAs was in the process of doing just that.

Apart from increased information, LAs might want to consider enhancing the support older users receive when making their choices and managing DPs. The administrative burden associated with employing PAs, for example, was a strong enough motive to drive some of the interviewees' choices in this study. Similarly, for all its benefits, choosing and managing a PA was still associated with higher anxiety among interviewees in this study. This outcome of the choice process seems to mimic previous results that date back to the evaluation of the Individual Budget experiment (Glendinning et al. 2008; Netten et al. 2012), suggesting that not enough has been done in this area.

This thesis has also reinforced the importance of continuity, particularly for people with dementia. This is in line with studies from the health sciences, that have identified continuity and quality of the relationship with the carer as an important determinant of the quality of life and anxiety of people with dementia (Ablitt et al. 2009; Qazi et al. 2010; Nelis et al. 2012; Clare et al. 2014). Commissioning officials from LAs should consider continuity of staff as a key quality indicator in their commissioning practices of home care – also for LA-managed care – particularly for older users with dementia. This finding should also be translated into the management practices of home care agencies, particularly in terms of the management of

their human resources. The extent to which this is possible is evidently linked to available resources, and cannot be decoupled from the wider discussion about funding long-term care in England.

Although carers were not directly covered in this study, its findings have yet another important policy implication for the care workforce in the context of choice and competition in long-term care, particularly in the English case. The importance of relationships for the satisfaction of users and the salience of continuity, particularly for users with dementia, were both well established in this thesis. These findings reinforce the importance of the workforce to achieve quality of care, in line with the previously discussed arguments (see Chapter 2) about the “physical” limits to achieving productivity gains at the expense of time to deliver care. Continuity, and maintaining relationships, obviously further constraints the scope for productivity gains in long-term care, for example, because the same carer must go to the same user, particularly as users clearly associated “time-trial” care (i.e. care delivered in the shortest amount of time possible) with poor quality. In England however, the development of competition and choice have taken place against a backdrop of marked budgetary constraints, that have exerted a well-documented negative impact on the care workforce, namely increasing staff turnover (Hardy & Wistow 1998; Hardy et al. 1999; Ware et al. 2003; Wilberforce et al. 2011; Glendinning 2012). Lewis and West (2014) have recently made a similar case about the negative impact that policy developments in the English long-term care system have had on the conditions to develop relationships. Their arguments are particularly pertinent in the context of LA-managed care and commissioning practices, but the findings of this thesis nevertheless validate their conclusions also for DP users.

7.4 LIMITATIONS, STRENGTHS AND FURTHER RESEARCH

One common issue with qualitative research methods is the possibility of generalisation of findings and sample size. The commonly referred practice in qualitative research is to collect data until the point where *theoretical saturation* is reached, i.e. until new observations added to the sample produce no new information, and when all variations have been identified (Guest et al. 2006; Bowen 2008). At the same time however, theoretical saturation is a relatively elastic and vague definition, and many question the validity of the concept as a yardstick of research quality when not using grounded theory, i.e. outside the particular research methodology for which the concept was devised (O’Reilly & Parker 2013). Nonetheless, Guest, Bruce and Johnson (2006) indicate twelve as the tentative sample size after which most codes have stabilised, i.e. after which little new information is being provided by additional data. The sample size in the present study is relatively small –

twenty-four individuals in total. This is due to time and resource constraints of conducting research in the framework of a PhD dissertation not attached to a larger project, as was the case here. However, during the process of analysing the data, it was also evident that most codes were devised in the analysis of the first interviews; later transcripts did not fundamentally change these codes. Additionally, the fact that all interviewees were asked a similar set of questions, rather than using a totally unstructured or exploratory research design, further balances the issues raised by the relatively small sample used (Guest et al. 2006). It should be stressed again that it was never the aim of the study and research methods employed to have a representative sample in the probabilistic sense.

One important aspect to bear in mind regarding the sampling procedure used in this thesis is the possibility for selection bias. DP users are unlikely to be a random sample of older users of publicly funded long-term care in England. Of particular relevance to this thesis, they might value relational aspects of care more than LA-managed care users and this might have compelled them to choose DPs. Users of care who value relationships with carers the most may have self-selected into DPs and therefore the salience of the relational aspects of care established by this thesis might be the result of this self-selection. To the degree that this selection bias is present, this would limit the possibility to extrapolate the findings to the wider population of users of home care in England. It is important to consider the scope for self-selection that the sampling process used entails. At the same time, however, it is important to consider two mitigating aspects. Firstly, even if self-selection exists, the findings of this thesis would still be relevant for older DP users, which represent a non-neglectable share of older users of care in England. Secondly, while it was clear that the relational aspects of care drove the decision to take-up DPs for some interviewees – i.e. they may have self-selected into DPs – for many other DP users interviewed this was clearly not the case – i.e. it seems less likely that they self-selected for these reasons. The findings regarding relationships were themselves nuanced and could thus allow for some extrapolation beyond DP users. For example, the unwillingness of many to employ relatives or friends could be an important factor for those on LA-managed care, since this was also the case for those using home care agencies. Similarly, greater leeway in defining care tasks was also acknowledged by purchaser-type users who had long tenured paid agency carers, which provides further credence to the generalisation of this finding to users of care in general. Finally, the study investigated the trade-offs that older people (in this case DP users) made in deciding how to obtain their care and these hint at some of the factors that might shape the experiences of non-current DP users.

Despite the fact that qualitative research methods can more adequately be employed to get detailed recollections of past events (Lewis 2003), there is nonetheless scope for some degree of recall bias with the research design used in this study. Alternatively, one could have employed a different study design, where the decision-making process of older DP users would have been assessed at the moment of making the initial choices – i.e., when they opted for the DP – and then followed up some time later. This study design would have for example greatly diminished the risk of recall bias. Time and resource limitations, and the possibility that interviewees would drop out of the study between the two periods of assessment, precluded this study design from being adopted.

A significant share of interviews took place with proxy respondents (see Section 6.2), particularly with those older DP users whose health condition affected their ability to express themselves, or give informed consent to participate in the study (see section 5.1.4), for example, due to dementia or multiple sclerosis. The challenges involved in interviewing people with dementia, and the potential for a response bias to arise due to the use of proxy respondents, are well known in qualitative as well as in quantitative research (Ettema et al. 2005; Baalen et al. 2011). In particular, proxies' answers are usually deemed as less reliable when questions relate to sensitive, personal or highly subjective matters (Kaye 2007). This potential bias is somewhat tempered if proxies have close relationships with the user, in which case the consistency of proxies' answers is likely to be higher (Lee et al. 2004). Bearing this in mind, as well as the fact that the decisions made in the context of dementia are likely to be deferred, or joint decisions made with close relatives, it was decided to interview proxy respondents. When relevant, it was also thought best to probe them about their perceived views of their relatives' (i.e. the users) preferences (see section 5.1.4). As users of dementia are liable to make up for an increasing share of users of PBs, leaving out their experiences of choice altogether would have limited the salience of the research.

In many instances, it was fairly clear that proxies were echoing the user's own voice in their narratives, for example, when they referred to the preference of being cared for at home, or to the benefit of having continuity of care. In some matters, however, proxies might have coloured the views of the user with their own, or might have even provided their own views rather than that of user's. For example, when referring to the need to trust the carer because their relatives could be vulnerable to abuse, proxies were likely referring to their own worries. Given the cognitive condition of many of the users, it was not always possible to confirm whether the narratives offered by proxies mirrored the users' own. There was, however, a marked likeness between many of the issues raised by proxies of users with

dementia, as well as their actual narratives and the ones expressed directly by older DP users without dementia. This consistency in itself is not sufficient to rule out the possibility of response bias by proxies - one would have had to compare their answers with those of their relatives and not with other unrelated older users of DPs. However, the consistency of issues and narratives can still be taken as a further reassurance of the salience of the issues raised in their narratives.

Still pertaining to the use of proxies, some of the choices (e.g. deployment of the DP) might reflect proxies' own preferences, particularly in the cases where proxies were themselves the PAs. Regarding this issue however, the exploration of the narratives of proxies provided fairly strong evidence that their choices had mostly been driven by concerns for their relatives' health and wellbeing rather than self-interest. In fact many of the choices made by proxies had actually implied sacrifices, such as giving up paid work.

The empirical study was conducted in the greater London area to facilitate transportation and gathering of information as the researcher was residing in London when the fieldwork was carried out. Some of the findings will therefore reflect the context (e.g. urban) of the LAs participating in this study. At the same time, some categories of DP users, namely those from ethnic backgrounds, were excluded from the sample. Despite this, the nature of the phenomenon studied is broad enough to afford some degree of generalisation and comparability with other studies, geographic locations or user groups. Similarly, the characteristics of people interviewed (e.g. the inclusion of people with dementia and frail condition), should also reinforce the relevance of the findings beyond the current study.

These limitations notwithstanding, this thesis provides a novel insight into the role played by relationships in the choices and experience of older people using DPs in England. Research thus far has focused on the role of relationships in residential care for older people (Nolan et al. 2006; Wilson et al. 2009) or in home care for disabled people of working age (Leece 2010). To date, however, there has not been any study addressing the impact of relationships in choices and experiences made specifically in the context of older people cared for at home in England. This thesis contributes to bridging that gap.

Furthermore, the sample comprises a wide range of older people receiving DPs. These include older people with physical impairments and people with various stages of dementia, albeit the latter were only interviewed through their proxy respondents. One should be cautious about generalising from qualitative studies, particularly those involving a relatively small sample such as this one. Nonetheless, the wide variety of users interviewed does

provide a comprehensive account of how relationships, and the concept of the user as co-producer of care, impact choices and experience of care across a wide range of circumstances and personal characteristics. While the qualitative research methods employed may somehow hamper generalisations, they are a unique tool to understand decisions, principles and behaviours (Ritchie 2003). In other words, the findings provide insights into the underlying processes and motivations for older DP users, and thus can contribute to a better understanding of their choices.

Despite the relatively small sample, this thesis also allowed for a systematic exploration of other factors that could also have impacted choices and experiences of care and the different views expressed by users concerning the role of relationships. Among these factors were living arrangements and social networks, institutional differences between LAs, health condition and age, tenure of the paid carers. This further strengthens the robustness of the findings. There were, however, two potentially important factors that could not be thoroughly examined and that merit further research: the size of the care package and the socio-economic condition of users.

This thesis also benefited from synthesizing the rationales and perspectives from mainstream economic theory, on the one hand, and feminist and disability critique, on the other hand. While these streams of theoretical thought have been at the forefront of the debate regarding choice on long-term care, and have underlined much of the research undertaken on the subject (see Chapter 2), they are often portrayed as diametrical opposites. This thesis has gone some way into arguing that both perspectives may actually supplement each other in the analysis of the behaviour of older users of long-term care.

As recognised above, this thesis is nonetheless quite exploratory, not only in terms of some of the issues it raised, but also in terms of the methods and sample used. There is, therefore, ample scope to build on the results of this thesis to enhance the knowledge about choice in long-term care.

One of the possibilities for further research is to understand the extent to which the choices made reflect deeply engrained differences in preferences of older users for closer or more detached relationships with carers. Given the exploratory nature of this study and its sample size, one could not entirely rule out that the purchaser-type users had more detached relationships with their carers because they had fewer possibilities to develop them. One can thus only wonder if the purchaser and employer-type users of this study are really reflecting broader differences regarding the preference for closer or more detached relationships

among older people. A follow-up study could also further investigate what factors may be correlated with these differences, such as class, gender, existence and quality of other relationships.

This thesis has clearly established the experience good nature of long-term care, namely regarding its relational nature. In such circumstances, having information about the characteristics of carers (particularly PAs) is key to bringing about the right matches (Nelson 1970), particularly when changing PAs might involve a psychological cost. It was obvious in this study, however, that older users faced significant information barriers when searching, particularly regarding their choice of PAs. Forder, Knapp and Wistow (1996) had previously warned about some of the difficulties prospective users of care might have in gathering information on quality, particularly when this concerned intangible outcomes. Relationships are obviously an example of such intangibles; it would be pertinent to explore whether information about this outcome could be conveyed and how.

Another potentially salient possibility for further research is to explore the concept and implications of long-term care as a morally contested commodity as briefly discussed above. Here the possibilities are several. Some users clearly expressed concerns that the cash nexus, i.e. the market, would pollute their existing friendships or kinships. Others, however, seemed content to employ and pay friends or relatives and thus juxtapose an employment relationship to pre-existing emotional bonds. In view of this, it is not clear where exactly the moral boundaries of long-term care lay as a commodity. The role played by reciprocity in this morally contested market also merits further exploration.

Finally, this thesis researched the issue of relationships and choices in long-term care through the lens of older DP users. The voices of paid carers (whether PAs or agency workers) were thus mostly absent from the narratives analysed in this study. It would be pertinent to investigate whether carers feel the same way about how relationships evolve in care, how their views may be different depending on being a PA or agency carer, or how paid carers see the reciprocal relationships in care.

7.5 CONCLUDING REMARKS

This thesis has demonstrated the importance of relationships in the choices of older users of DPs in England. This thesis found that relationships played a role in the choices of some older DP users, namely those that wanted to have a particular person as their paid carer, those that wanted to ensure continuity, or those that sought to have companionship besides care.

However relationships could also be important to determine the decision not to employ a relative or friend, as many older DP users expressed reservations in mixing friendship or kinship and employment relationships. Furthermore, many interviewees clearly derived satisfaction from the closer relationships that they enjoyed with their paid carers, and many went as far as defining these relationships as akin to kinship.

Where the importance of relationships is more evident however, is how it shapes the experience of care. On the one hand, relationships have an intrinsic value as an outcome of care itself, for example, as a source of social and psychological support, and as an important element in improving the wellbeing of people with dementia. On the other hand, relationships are also valued for what they help to achieve, i.e. they have an instrumental value. Establishing a rapport with a carer could thus improve the experience of receiving personal care, enable the carer to know the user's needs and preferences, allow users to receive care in line with their preferences, and in some cases even allow users to receive more care than they had paid for. This thesis also found that relationships, insofar as they are associated with continuity, are key for older people with dementia to cooperate in care provision, i.e. relationships are an important element of the concept of user as a co-producer of care. Relationships could thus shape what care was provided, how it was provided and when.

Relationships in long-term care are also quite differentiated. While virtually all interviewees recognised the instrumental value of relationships, this does not mean that all interviewees weighed the relational aspects of care in the same way when they made their decisions. Not only did some interviewees deliberately choose not to employ relatives or friends as their PAs, but many opted instead to purchase care from home care agencies, as they considered it more important to have appropriate backup or less administrative burden. Not all interviewees expressed a preference for deep and close relationships with their carers. Those that purchased care from agencies in fact preferred to have a more professional-like relationship with their carer. On the contrary, those who have employed a PA developed friendships or fictive kin relationships with their carers, even those with whom they were not initially acquainted with. This clearly contributed to their satisfaction with care received.

The findings of this thesis provide evidence of the status of relationships as an outcome of care, and are thus in line with a wide body of theoretical literature that defines care as a relationship. However, this thesis also contributes to advancing the theoretical understanding of caring, by introducing the concept of relationships as instruments for the delivery of care.

This thesis also found reciprocity to be a key element in the definition of caring relationships. Accounts of symbolic non-monetised gift exchanges were clearly matched with closer bonds established with carers, and notably absent in the narratives of users that purchased care from home care agencies. This challenges the view of caring relationships as being fundamentally asymmetric, and the image of older users of care as unable or diminished in their ability to reciprocate. The fact that older DP users employing PAs engaged in reciprocal exchanges beyond the employment relationship, suggests also that reciprocity can be akin to an efficiency wage, i.e. it can reinforce ties and reduce turnover, in the context of a morally contested commodity. These reciprocal gifts can thus serve to reward in-kind attributes that cannot be paid in cash such as affection and emotional bonding.

The findings of this thesis thus provide a nuanced picture of the preferences and experiences of older users of long-term care. The possibility to directly employ a PA afforded by DPs seems crucial to the satisfaction of many users, while others clearly preferred to receive their care from home care agencies. Unlike some voices that have defended PAs as the preferred choice of care for older people, there seems to be a strong case for both home care agencies and PAs to co-exist in local care markets in England. In both cases, however, the findings of this study highlighted the importance of having agency over the choice of a particular carer, and over what care to receive, how to receive it and when. This should merit some reflection in the debate about how to improve choice in long-term care.

By confirming that care has a relational dimension that is relevant to users, this thesis has provided evidence that relationships are an important component of what makes long-term care an experience good. Furthermore, users of long-term care seem to have different preferences regarding their relationships with paid carers, and these relationships are very much determined by the interaction between the user and paid carer. This not only confirms the concept of the user as co-producer of care, but expands it to also include the relational components of care.

Chapter 8 : CONCLUSIONS

This thesis aimed to contribute to a better understanding of how older users of long-term care make their decisions regarding care and in particular how the relational and co-production aspects of care affect the choices of older people and their experience of care. These decisions are made in the context of user choice and quasi-markets. In order to understand the choices made by older users of long-term care, this thesis made the argument that it is first necessary to understand the characteristics of care as a commodity. An initial review of different strands of literature on choice, caring and long-term care (see Chapter 2), highlighted two important issues in this respect. Firstly, a significant body of literature defends the idea that care goes beyond the mere delivery of tasks to include a strong relational component, i.e. the rapport established with the carer is important to ensure the quality of care received. The second salient issue raised by the literature surveyed, was the notion of the user as a co-producer of care, i.e. being able to tailor care to one's preferences is an important determinant of satisfaction with care. Despite the wealth of research that user choice policies in long-term care have merited (see Chapters 2 and 3), there is a gap in empirically-based knowledge about the role played by relationships in the choices of older people, and how they impact other dimensions of choice.

Against this background and using England as a case study (see Chapter 3), the main research question is how and why users' experiences of care are affected by choosing to hire a personal carer rather than to acquire services from a formal provider. In order to explore this research question, two hypotheses were derived to guide the research (see Chapter 4):

1. Firstly, hiring a personal carer would entail higher satisfaction, compared with purchasing care from an agency, because it allowed the user to choose from whom to receive care, which should matter to the user if the relational aspects of care are indeed salient.
2. Secondly, hiring a personal carer would also imply increased leeway in defining what, when and how care is provided, as opposed to purchasing care from agencies.

To explore these two hypotheses, this thesis employed qualitative research methods (see Chapter 5), namely in-depth semi-structured interviews and Framework Analysis, on a sample of twenty-four older users of DPs from three LAs in greater London. The focus on DP users was triggered by the fact that they come closer to the notion of "consumers of care",

which underlines much of the discourse around choice and long-term care in England (see Chapter 3). The decision to analyse older users of DPs, rather than, for example, those of working age, was motivated by the fact that the former remain somewhat under-researched, and that DPs are still underused by older people in need of care.

The empirical findings of this thesis (see Chapter 6) can be summarised in four main points:

- i. Relationships can impact the initial choices made by older DP users. Many interviewees valued relationships high enough to opt for PAs, despite the additional uncertainty and administrative burden. Others had reservations about mixing employment with friendship or kinship, and thus chose not to employ an acquaintance as a PA.
- ii. Relationships can impact the experience of care because they have an intrinsic value, i.e. relationships are themselves an outcome of care; but also because they have an instrumental value in aiding or contributing to the delivery of care.
- iii. Relationships were markedly different between users. Those employing PAs valued the intrinsic value of relationships more, and established deep relationships with their paid carers. Those purchasing care from agencies valued relationships more as an instrument, and often deliberately sought to keep some emotional distance from their agency carers.
- iv. Reciprocity was a defining characteristic of relationships between users and paid carers in this study. Users that employed PAs engaged in symbolic non-monetised gift exchanges, while these reciprocity accounts were absent from the narratives of those that were purchasing care from agencies. While the latter stated their preference for more circumscribed relationships with carers, different deployment options offered more opportunities for reciprocation than others. Reciprocity was more restricted among purchasers of care due to home care agency rules.

Going back to the two hypotheses described above, the following conclusions emerge from this thesis. Regarding the first hypothesis, employing a PA and being able to choose the identity of the paid carer allowed older DP users to develop closer relationships with their carers, even if this implied higher anxiety when choosing a stranger as a PA. Older DP users who purchased care from home care agencies had much less leeway in choosing their agency carers, and reported much more circumscribed relationships. However this study found little evidence to contradict the view that these detached relationships actually corresponded to their wishes. For the latter group of users, delivery of care did not depend on close relationships with paid carers. The findings thus did not wholly support the first hypothesis.

Establishing a rapport with the paid carer (whether a PA or an agency carer) did, however, impact how care was provided, and the satisfaction derived from it was directly relevant to the second hypothesis under study. As the paid carer became familiar with the user, this allowed the former to anticipate the latter's needs and preferences. This was clearly on display among users with dementia, where continuity and familiarity contributed to improve the experience of receiving care. Incidentally, this also applied to people with dementia who had had the same long-standing agency carers. The rapport established with the PA could go as far as contributing to paid carers delivering more hours of care than they had been paid for. Directly employing a PA could yield greater power to determine care tasks, but besides this, the empirical findings of this thesis confirm that continuity and closer relationships with paid carers also work towards enhancing users' leeway to define what care to receive, how and when.

The findings of this thesis contribute to expanding the theoretical and empirical knowledge of the concept of caring, of the role played by reciprocity in caring relationships, and of the choices made with cash benefits in long-term care. Each is detailed below.

The concept of caring as encompassing a relational dimension of concern for the human being that exists alongside the physical dimension of care, and that distinguishes care from mere domestic labour, has long been advocated by the feminist literature (Gilligan 1993; Himmelweit 1999; Folbre & Nelson 2000). This is a facet that is confirmed by the findings of this thesis. The feminist literature, however, has often defined caring as an asymmetric relationship that stems from the inability of users of care to reciprocate (cf. Himmelweit 1999; Jochimsen 2003). This is a facet of care that the findings of this study do not wholly concur with. Instead, the findings seem to point to caring as having the potential to create an interdependent relationship between the user and the carer (Kröger 2009), built around reciprocal exchanges, at least among users employing PAs. Even though PAs provided care against cash payments, i.e. the provision of care was being monetarily compensated, there were reciprocal relationships established beyond those cash payments. Similarly, reciprocity was present not only within kinship or friendship relationships, for example, when users are themselves carers of other family members, but also between users and PAs who had not previously known each other. Although those purchasing care from agencies did not report these reciprocal relationships with agency carers, they also had more limited opportunities for reciprocity.

The findings of this thesis furthermore suggest that reciprocity can play a role similar to that of efficiency wages in labour economics (Akerlof 1982). Efficiency wages refer to wages paid

above the market wage in situations where employers may want to enhance the employee's loyalty, and avoid the costs associated with staff turnover and/or enhance productivity. Similarly, the gift exchanges in care could serve to cement relationships whose continuity is always uncertain, in the same way that relatives exchange gifts at designated times to strengthen ties that bind (Caplow 1982). The gift exchanges could also serve to motivate the carer's emotional engagement. The question is whether to pay extra wages to carers if one wants to ensure continuity or increased productivity. The answer may lie in the fact that care is not an ordinary commodity, particularly if it involves a strong relational component as this thesis has shown. Paying for love and a sense of caring may seem repugnant to both users and carers, but may be deemed acceptable if the "payments" are in-kind and take place in what users and carers see as a reciprocal relationship. Furthermore, reciprocity may affect the sense of loyalty of carers, by creating a stronger moral bond than financial incentives associated with higher payments.

Finally, user choice, and particularly DPs, has often been defended on the grounds that they allow users to employ their own carer (Moran et al. 2012). The findings of this thesis indicate that older DP users face trade-offs in their choices. Not all users value caring relationships in the same way, or value the same kind of care-giving relationships, i.e. not all prefer to hire PAs. One of the main advantages of DPs may thus be that they allow older users of DPs to be paired with their preferred and apparently dissimilar options in terms of relationships and deployment of DPs. This thesis seems to strengthen the case for having both PAs and agencies as valid options for older DP users in care markets at the local level. Despite the importance of relationships, they did not seem to constitute a strong obstacle to changing carers or agencies, whenever care provided was deemed unsatisfactory. The fact that many older DP users in this study had taken-up DPs in response to dissatisfaction with LA-managed care is also an indication of their willingness to switch agencies or PAs (although the sample did not include anyone who had switched from PA to purchasing care from a home care agency). Nonetheless, relationships do reinforce the character of long-term care as an experience good, i.e. one whose quality is difficult to judge before having experienced it. This has not been properly addressed in the discussion about user choice.

It is worth bearing in mind, however, that this study is still exploratory and based on a relatively small sample of older DP users. One should thus resist the temptation to generalise, or draw too strong inferences from the findings. Furthermore, the LAs covered by this study were situated in the greater London area, and some of the issues raised in this study may be more salient to urban places rather than to other locations. Although this thesis eventually

also included cases of users with dementia, it was mostly the voice of proxy respondents that was captured in these instances. It is therefore likely that the findings pertaining to users with dementia reflect mostly the views of their proxies.

This thesis has not however exhausted all relevant possibilities for research around user choice and long-term care. In fact its findings have probably uncovered new salient research possibilities. Among the possibilities for further research more directly pertaining to the findings of this study are the following. Given the exploratory nature of the study, one could only conjecture that choices and relationships with paid carers reflected also different preferences between users who hired PAs, and those that purchased care from agencies. Given that the latter also had arguably less leeway to develop those relationships, this is a matter that requires further study before more definite conclusions can be drawn. The hypothesis of reciprocity as a kind of emotional efficiency wage also needs to be further tested, for example, regarding the effect that in-kind exchanges may have in fostering the relational aspects of care, or enhancing continuity as opposed to financial incentives. This thesis afforded some glimpses of how users' choices are shaped by the fact that care is a morally-charged commodity – recall the reservations of many about employing friends or relatives – but limited understanding still exists on this issue. Another salient gap meriting further research is how care as an experience good, also in its relational component, impacts the need for and type of information for older users of care. Finally, it would be pertinent to supplement the views of older DP users expressed in this study regarding relationships and reciprocity with those of paid carers.

This thesis has modestly contributed to restate the salience of relationships in the context of long-term care and therefore for the choices made by older DP users. Rather than being a marginal concept, or one confined solely to the disability or feminist critique of the commodification of care, the relational aspects of care are very much at the core of what makes long-term care an experience good. For this reason, they should be considered in the theoretical and empirical research on the economics of care, as well as in the on-going policy discussion on user choice policies and quasi-markets in long-term care.

**APPENDIX A : INVITATION LETTER TO DIRECTOR OF
ADULT SOCIAL SERVICES FOR LOCAL AUTHORITIES**

Ricardo Rodrigues
[Contact details omitted due to
confidentiality]

19th December 2012

INSERT NAME

INSERT POSITION

INSERT ADDRESS

Subject: Request for help with study on older people using Direct Payments

Dear Director of Adult Social Services of the Borough of *[insert name]*,

I am conducting a study on the choices made by old-age users of Direct Payments (DP), which will be the basis of my PhD in Social Policy from the University of York. The aim of the study is to understand **why some users choose to hire personal assistants, while others use the DP to purchase services from agencies, and how this choice affects their satisfaction**. This study has received approval from the Ethics Committee of the University of York.

In order to conduct this study, I would like to kindly **ask for your collaboration in identifying potential interviewees** for the study, and to **ask for a meeting** where we could discuss how this could be done in the least burdensome manner for you and your staff.

To thank you for your help, I would prepare a short briefing note on the key findings and implications for adult social services in your area, whilst maintaining the confidentiality of interviews.

The enclosed summary information sheet contains more details on the study.

I do appreciate the many demands on your time, particularly at this time of the year, so would be keen to discuss the best way to carry out this research with the least possible extra work to yourself and your staff, and the most benefit to you in terms of delivering useful findings.

I would very much welcome the chance to discuss the study with you and answer any questions you may have. I am sending you a hard copy of this letter before Christmas and will aim to contact your office by phone in the first week of the New Year to follow this up.

I thank you in advance for your time and look forward to hearing from you.

Yours sincerely,

Ricardo Rodrigues
PhD Student, University of York

**APPENDIX B : INVITATION PACKAGE TO LA STAFF TO TAKE
PART IN THE INTERVIEWS**

Invitation letter for care managers of adult social services

Invitation to take part in an interview for a study

Dear Madam/Sir,

My name is Ricardo Rodrigues and I am currently a PhD student at the University of York. As part of my PhD thesis, I am conducting a study aimed at understanding the choices made by users of Personal Budgets (PB) that have taken up this benefit as Direct Payments (DP). I am trying to understand why, and how, users of DP use the benefit in different ways, namely to pay their relatives, employ a personal carer, or purchase services from an agency, and how this impacts their satisfaction.

For this study, I will need to interview a number of old-age users of DPs in this local authority. Before that, however, I need to gather detailed information and properly understand how DPs are provided, and what choices their holders are given. This includes knowing how eligibility for the DP is carried out; what options users are provided with; what information is available, and what constraints they are faced with. For this, it is paramount that I speak to those more directly involved in the process, such as yourself. The Director of adult social services has authorised me to forward this invitation to you to kindly invite you to participate in this study.

I would be most grateful if you could help me with this study. I would be happy to agree to a date, time and place of your convenience to conduct the interview, which should not take more than 30 to 40 minutes. The contents of this interview will supplement the information that I have already gathered by means of literature and internet search.

The confidentiality of whatever you say and your identity will be assured. You have been randomly selected to receive this invitation package. If you agree to participate your identity will not be provided to anyone. My supervisors and I will be the only ones accessing the contents of the interview. The contents of the interview will be summarised in a text that will be sent to you for prior approval and validation. This will enable you to reject any information that you consider inappropriate, or that you disagree with, without any questions being asked.

Attached to this letter, you will find more information about the study and what your participation entails. Please take some time to read it. If you are interested, please fill in the attached response form for contact, and mail it to me using the pre-stamped envelope provided, or send it by e-mail and I will contact you.

Thank you very much in advance for your time.

Sincerely yours,

(Ricardo Rodrigues)

[Contact details omitted due to confidentiality]

PhD thesis on ‘Understanding choices made by old-age users of Direct Payments’

Information leaflet

I would like you to take part in a research interview about the process of providing old-age people with Direct Payments. This leaflet provides you with more information about this research and what will happen if you decide to take part.

Who am I?

My name is Ricardo Rodrigues and I am a PhD student at the University of York - Department of Social Policy and Social Work. I was born in Portugal, I am 34 years old, I am an Economist by training and I reside in London and Vienna, Austria. As part of my occupation I have talked with people that receive care before, as well as public officials in a number of countries.

What is this study for and why?

This study is part of my PhD thesis in Social Policy at the University of York. When old-age people need help, it is sometimes difficult to make decisions about what care is needed and who should provide it in their homes. This study aims to understand how, and why, some old-age people prefer to pay a relative or employ a personal carer, while others buy services from an agency provider. Ultimately, this study could help improve services for people across the whole of England. This study serves no political or commercial purpose and I must carry it out in order to complete my PhD.

Who do I want to talk to?

I would like to talk to local authority staff who are directly involved in assessing, counselling and managing the processes of old-age people that are applying or benefiting from Personal Budgets and Direct Payments. Alternatively, I would like to talk to staff members that may not be directly involved in these tasks, but that supervise them or have knowledge of the whole process.

How will this study be done?

I will be talking to you about the process of assessing eligibility and the referral process of Personal Budgets and Direct Payments; the options available to users that choose to receive their Personal Budgets as Direct Payments; and the providers operating in the local authority's area. For example: what options are made available to users that take the Personal Budget as cash (i.e. as a Direct Payment)? What information, help or counselling is provided to users who decide to take cash? What steps does the local authority take to incentivise increased supply from agency providers and personal assistants?

The information gathered in the interviews will serve as contextual information to better understand the answers of old-age users of Direct Payments that I will subsequently interview. It will supplement the information about Direct Payments already gathered on the internet and by literature review. It will also serve to check the terminology used in the interviews with old-age people.

These interviews will not be in a typical 'question and answer' format, more like a normal conversation where I would listen to what you have to say about the process of assessing and providing Direct Payments. This conversation is likely to take no more than 30 to 40 minutes.

Do I have to take part?

No. You can choose if you want to take part in this study or not.

What will happen if I decide to participate?

If you send me the response form, I will then contact you to tell you more about this research, and answer any questions or concerns you may have about taking part in it.

If you decide to participate, we can agree on a date, time and place of your choice for me to come and talk to you – this can be at your place of work or other.

What if I change my mind?

You can leave the study at any time, even during the interview. I would thank you nevertheless, and no questions or justifications will be asked.

Will anyone know what I say?

I will not inform anyone that you have taken part in this study. Your hierarchical superiors will not know whether or not you participated for you were chosen randomly.

I might use your words in my PhD thesis, or in reports or articles that I write, but I will never use your name or include any details that could allow you to be identified. The contents of the interview will be summarised in a text form, and sent to you for approval. You may edit its contents, deleting all sentences or information that you are not comfortable with, or if you have changed your mind about what you said. You do not need to justify these changes.

However, if you tell me that you or someone else is at serious risk of harm I may be legally obliged to pass on this information to someone else. In the extremely unlikely event that this happens, I would talk to you before passing this information to anyone else.

Confidentiality

I would like to tape record the interview, so I have a record of it and to help me compile the information gathered. The tape recording will be kept safe in a locked drawer. Any transcriptions of this or conversations taking place by e-mail, will be kept secure in electronic form with a password on the computer, and any copies will be kept safe in a locked drawer. The tapes will only be listened to by myself or my two supervisors and no one else.

What will happen to the results of this study?

Talking to you will help me to understand how, and why, old-age people make their choices when they receive cash benefits from local authorities. I can then interview old-age people using Direct Payments, and compare the answers of people that have chosen to use this benefit differently. This is the main topic of my PhD thesis. I may use the information to write articles for journals and for presentations at conferences. Once I have completed my thesis, I will write to you and tell you what I have learnt. I think you will find it interesting.

Who has paid for this study?

I am funding my own studies by working part-time as a researcher. No one else has funded this study.

This study has been reviewed by the University of York's Department of Social Policy and Social Work Ethics Committee. They have made sure that the research protects and does no harm to the people that take part in it.

How do I tell you if I want to take part or if I have questions?

If you are interested to take part, or want more information, please fill in the enclosed response form and send it to me using the pre-stamped envelope that is provided, or write me an e-mail at my University e-mail [contact details omitted due to confidentiality] so that I can get in touch with you. You can also contact me using the above mentioned means if you have any doubts concerning this study or your participation.

If you are concerned about any aspects of this study, please contact any of my supervisors:

Prof. Caroline Glendinning

[Contact details omitted due to confidentiality]

Dr. Richard Cookson

[Contact details omitted due to confidentiality]

THANK YOU VERY MUCH FOR YOUR ATTENTION.

**APPENDIX C : INVITATION PACKAGE TO DP USERS TO TAKE
PART IN THE INTERVIEWS**

Information for users of Direct Payments participating in the study

Dear Madam/Sir,

My name is Ricardo Rodrigues and I am currently a PhD student at the University of York. Your local authority has forwarded this invitation to you to kindly invite you to participate in a study that I am conducting. This study is about understanding the choices made by users for help and care services in their home.

This study is part of my PhD studies, it is independent of any political or commercial interests, and its findings could potentially help improve the way help and care services are organised across the whole of England.

For this study, I need to interview a number of people that receive a cash benefit from local authorities called Direct Payments. This is to find out how people choose the help they receive, how satisfied they are with the help they receive, and what they would like to improve. This will help me complete my PhD thesis, and I hope it will also contribute to better support people who need help in their home.

I am most grateful to you for agreeing to take part and help me with this task. Finally, the contents of this interview will be strictly confidential and I will not share them with anyone.

Ricardo Rodrigues

PhD Student

March 2013

PhD thesis on 'Understanding choices made by users of care'

Information leaflet

I would like you to take part in a research interview about the choices you have made in order to receive help in your home. This leaflet tells you what this research is about, and what will happen if you decide to take part.

Who am I?

My name is Ricardo Rodrigues and I am a PhD student at the University of York, Department of Social Policy and Social Work. I was born in Portugal, I am 34 years old, I am an Economist by training and I reside in London and Vienna, Austria. As part of my occupation I have talked with people that receive care before, as well as public officials in a number of countries.

What is this study for and why?

This study is part of my PhD thesis in Social Policy at the University of York. When people need help (for example to prepare meals or to help them get dressed), it is sometimes difficult to make decisions about what they need and who should come to one's home to give it. This study aims to understand why some people prefer to pay a relative or employ a personal carer, while others buy services from a home support agency. Ultimately, this study could help improve services for people across the whole of England. This study serves no political or commercial purposes and I must carry it out in order to complete my PhD.

Who do I want to talk to?

I would like to talk to people who receive a Direct Payment and have used it to employ a personal carer, or to buy care services from a home support agency. If you have started to receive a

Direct Payment from [LA name omitted due to confidentiality] Council in the last year, I would be interested to talk to you.

How will this study be done?

I would like to hear about how it was when you looked for care and had to decide on how to use the Direct Payment. For example: how did you feel about the options you had? How did you decide on what help to receive? And how happy are you with the help you get?

These interviews will not be a typical 'question and answer' but more like a normal conversation during which I would hear what you have to say about this topic. It is likely to take no more than an hour.

Do I have to take part?

No. You can choose if you want to take part in this study or not. You can leave the study at any time if you change your mind, even during the interview. I would thank you nevertheless, and no questions or justifications will be asked.

What will happen if I decide to participate?

If you send me the response form, I will then contact you to tell you more about this research and answer any questions or concerns you may have about taking part in it.

If you decide to participate, we can agree on a date, time and a place of your choice for me to come and talk to you – it can be at your home or any other place you prefer. If you wish, your spouse, a relative, friend or neighbour can be present when I talk to you. If you pay someone to help or care for you, I would prefer if this person is not present, because some of the questions may be about her/him.

Will anyone know what I say?

I will not tell anyone what you have said during the interview. The services or benefits you receive from [LA name omitted due to confidentiality] Council will not be affected.

I might use your words in my PhD thesis, or in reports or articles that I write, but I will never use your name or include any details that would allow you to be identified.

However, if you tell me that you or someone else is at serious risk of harm, I may be legally obliged to pass on this information to someone else. In the extremely unlikely event that this happens, I would talk to you before passing this information to anyone else.

Confidentiality

I would like to tape record the interview, so I have a record of it and to help me compare it with other interviews. The tape recording will be kept safe in a locked drawer. Any transcriptions of this or conversations taking place by e-mail will be kept secure in electronic form with a password on the computer, and any copies will be kept safe in a locked drawer. The tapes will only be listened to by myself or my two supervisors and no one else.

What will happen to the results of this study?

Talking to you will help me understand how, and why, people make their choices when they receive Direct Payments. This is the main topic of my thesis and I will write about what I have found in my PhD thesis. I may use the information to write articles for journals, and for presentations at conferences. Once I have completed my thesis, I will write to you and tell you what I have learnt. I think you will find it interesting.

Who has paid for this study?

I am funding my own studies by working part-time. No one else has funded this study.

This study has been reviewed by the University of York's Department of Social Policy and Social Work Ethics Committee and by the [LA name omitted due to confidentiality] Council. They have made sure that the research protects and does no harm to the people that take part in it.

How do I tell you if I want to take part?

If you are interested in taking part, or want more information, please fill in the enclosed response form and send it to me using the pre-stamped envelope that is provided. Alternatively you can write me an e-mail at my University e-mail [e-mail address omitted due to confidentiality], or contact me on my mobile [contact details omitted due to confidentiality] so that I can get in touch with you.

If you have any doubts concerning the study or your participation, please contact the following person within the [LA name omitted due to confidentiality] Health and Social Care Unit who will be happy to answer any questions:

[INSERT NAME AND CONTACTS]

THANK YOU VERY MUCH FOR YOUR ATTENTION.

**PhD thesis on 'Understanding choices made by users
of care'**

RESPONSE FORM (Users of Direct Payments)

Consent to be contacted

Please tick the boxes to indicate 'YES' to the following statements:

I am happy for you to contact me about this study

I understand that I am free to withdraw from this study at any time

Please sign below to give your consent to be contacted:

Name (PRINT): _____

Signature: _____

Date: _____

Your contact details

Please provide your contact details below:

Address: _____

_____ **Postcode:**

Tel. no. (landline or mobile if preferred): _____

Email (optional): _____

Best times to be contacted: _____

Please return this form to Ricardo Rodrigues in the **FREEPOST** envelope provided (*no stamp or address required*).

Thank you very much.

APPENDIX D : CONSENT FORM FOR LA STAFF

PhD thesis on ‘Understanding choices made by old-age users of Direct Payments’

CONSENT FORM FOR PARTICIPATION (Care Managers)

Thank you for thinking about taking part in this research.

Please tick the boxes.



Yes



No

I have read the information leaflet

I have had time to think about taking part

I have asked questions if I wanted to

I know I do not have to take part

I know I can stop taking part if I want to

I agree for you to record our conversation

I agree to take part in the research

I know that the contents of the interview and my identity will be kept confidential

Participant's name

Signature

Date

Student's name

Signature

Date

APPENDIX E : CONSENT FORMS FOR DP USERS

PhD thesis on 'Understanding choices made by old-age users of care'

CONSENT FORM FOR PARTICIPATION (Users of Direct Payments) [LA#1 and LA#3]

Thank you for thinking about taking part in this research.

Please tick the boxes.



Yes

No

I have read the information leaflet

I have had time to think about taking part

I have asked questions if I wanted to

I know I do not have to take part

I know I can stop taking part if I want to

I agree for you to record our conversation

I agree to take part in the research

I know that any help or services I receive will not be affected, whether I take part or not

I know that if I tell you that I or someone else is at risk of harm you may have to pass on this information

Participant's name

Signature

Date

Student's name

Signature

Date

CONSENT FORM [LA#2]

STUDY PROJECT - DIRECT PAYMENTS, March 2013

Service User Name:

CCIS:

I hereby give my consent to take part in the research into the study of Direct Payments conducted by Ricardo Rodrigues, a PhD student from the University of York Department of Social Policy and Social Work and organised by the London Borough of [name omitted due to confidentiality] Adult Social Services.

I fully understand:

- The meeting will be recorded for analysis purposes, which will be retained in a safe and secure manner, and destroyed at the end of its use, which is likely to be on or around April 2014.
- I can ask questions during the interview or stop at any time I choose, or not continue with the study if I so wish.
- All information I have shared will be treated with complete confidentiality, but as with any information which comes to the Council's attention, it may be used by the Council to prevent or investigate any fraud or criminal offences.

Signed: _____ Date: _____

Signed: _____ Date: _____

Ricardo Rodrigues, Research Student (To retain original copy)

APPENDIX F : TOPIC GUIDES FOR INTERVIEWS

Topic guide for interviews with care managers

Ask ahead for copies of any material provided to users of PB and Direct Payments.

Process of assessing eligibility and referral *[most questions refer to the average holder of a PB or DP]*

What are, in detail, the criteria for providing Personal Budgets (PB)? [prompts: not only physical health, but also cognition and their social networks]

Could you describe the general condition [prompts: not only physical health, but also cognition and their social networks] of people that request Direct Payments (DP) in this local authority?

To what extent are old-age persons (or their relatives) involved in the assessment and definition of their own needs?

Could you tell me the typical approach for explaining what the holder of a PB is entitled to? [prompts: cash, care services managed by the local authority]

In your opinion, how much leeway do PB and DP holders have to define their work package?

Options provided *[most questions refer to the average holder of a PB or DP]*

What options are available to people who want to take their PB as cash?

Considering the 3 options that we are interested in analysing within this study: pay informal carer/relative; hire professional personal assistant; purchase care from agency provider...

Once people have chosen to take cash, what is then your involvement [prompts: search process; assurance that people get adequate care, help with paperwork]?

What information/help/counselling is provided to users that decide to take cash? [prompts: list of providers – follow-up: how is this collected and kept up-to-date? Leaflet explaining obligations, tailored help in searching/hiring/negotiating]

Could you explain what are the constraints involved in each of the options on which we are focusing?

To what extent are holders of DP able to use them to employ relatives/people they know? What do you think about this?

How far are you involved in the search and negotiation process for agency providers or hired personal carers? [prompts: list of providers – ask for a copy; aid in recruiting and hiring of carers; pointing out existing providers/internet sites/advocacy groups]

Does the local authority favour any particular option?

We have thus far concentrated on what could be considered as an average PB or DP holder. Could you explain how the above processes change in the presence of people with a) more severe care needs, b) cognitive impairment or c) a diminished or inexistent social network?

Care market and existing formal providers

Could you provide a general overview of the existing agency providers operating in this local authority? [prompts: number and diversity – ownership, target groups, size]

How diverse do you think the care options provided by formal providers are? [prompts: ask for examples of services provided, timing for provision of care]

Could you tell me how you think the interaction is between holders of PB or DP and providers? [prompts: negotiation of tasks, change of carer, timing for provision of care]

How easy do you think it is to hire personal assistants in this local authority?

How have providers evolved since the introduction of PB?

Do you know of any issues that have arisen between users of PB or DP, and providers or personal assistants?

What steps does the local authority take to incentivise an increased supply from agency providers (number or diversity of care provided) and personal assistants?

Views on personalisation of care and old-age people's choices

In your opinion, what do old-age people value more when searching for care?

In your opinion, what factors explain why some old-age people choose to pay relatives, hire personal carers, or purchase services?

What is your opinion on the personalisation of care and PB?

What are the advantages and disadvantages you foresee in the use of PB or DP for old-age people?

Topic guide for the interviews of users of Direct Payments

Purpose of the study: PhD research on how old-age people in need of care make their choices about care. This could contribute to improving the support old-age people get, and help us understand what they need to make their choices and feel supported and secure in the process. **Assure that the contents of the conversation will be strictly confidential and will not affect in any way the services or benefits they currently receive. Ask permission to tape the interview – as it would greatly facilitate the analysis afterwards. Re-state that interviewee may quit the interview at any stage without any questions being asked.**

In this interview I would like to talk to you about the help you get with the Personal Budget or Direct Payment from the local authority.

Contact with the LA

Looking back to the moment you went to the local authority (LA) because you needed help...

How did you contact the local authority? [prompts: whom did you talk to; did they explain what you could buy with the Direct Payment; what advice you received]

In your opinion, what was important for you back then? [prompts: what care did you need/want; urgency]

Why did you decide to take the PB as cash?

How did you take part in the decisions / Could you choose what you wanted?

What options were you offered and by whom? [prompts: care manager, websites, word of mouth]

How satisfied/supported did you feel about the way the whole process went? [prompts: supported by your spouse, a relative, a friend]

Making choices with the DP

Why did you decide to [pay your relative/hire a personal carer/buy care from an agency provider]? [prompts: you already knew him/her, price, and lack of options]

Was this what you really wanted? >>> Why couldn't you get what you really wanted? [prompt: were there any other choices; lack of money; lack of acquaintances]

What was the most important thing for you when you decided to [pay your relative/hire a personal carer/buy help from an agency provider]? [prompts: knowing the carer, safety, getting what you want]

Why didn't you choose [refer to alternatives]?

Could you describe to me how you searched for this carer/agency provider [professional carer or agency provider ONLY]? [prompts: internet, newspaper ad, help from the care manager, word of mouth]

Who decided what help you would get? [prompts: what tasks, what time, by whom; care manager]

The relationship with the carer/care received (including those purchasing care from an agency provider)
--

Could you describe to me your relationship with your carer?

Has this relationship changed over time? How did it change? [prompts: tease out in relation to the previous answers].

How important is your carer to you [relate back to the words of the person in the first question]?

Did you know him/her before? Was this important for you? Is it important now?

Can you describe to me how you agreed with the person that helps you what kind of help you receive, and when and how he/she gives you this help? [prompts: payments, regulations, rules on how to spend the PB, social security or tax payments]

What were for you the most important things on which to agree [relate to previous question]? [prompts: when to come, what to do; how to do it – relate to care tasks mentioned earlier].

How do you feel about [paying your relative, being the employer/manager, in your relation with the agency provider]?

Current care and satisfaction

How satisfied are you with the help you receive / what do you like the most about the help you receive?

Was it always like this? What changed in terms of how happy you are with the help you receive?

What would you improve?

Do you feel you have control over the help you get? How important is this for you?

LIST OF REFERENCES

- Ablitt, A., Jones, G. V. & Muers, J., 2009. Living with dementia : a systematic review of the influence of relationship factors. *Aging & Mental Health*, 13(4), pp.497–511.
- ADASS, 2011. *Personal Budgets Survey March 2011 - Final Results*, London: Association of Directors of Adult Social Services.
- ADASS, 2010. *Personal Budgets: Council Commissioned Services Advice Note*, London: Association of Directors of Adult Social Services.
- ADASS, 2012. *The Case for Tomorrow*, London: Association of Directors of Adult Social Services.
- Adult Social Care Statistics, 2013. *Community Care Statistics: Social Services Activity, England 2012-13*, Health and Social Care Information Centre.
- Akerlof, G.A., 1982. Labor Contracts as Partial Gift Exchange. *The Quarterly Journal of Economics*, 97(4), pp.543–569.
- Akerlof, G.A., 1970. The Market for “Lemons”: Quality Uncertainty and the Market Mechanism. *Quarterly Journal of Economics*, 84(3), pp.488–500.
- Anttonen, A., Sipilä, J. & Baldock, J., 2003. Patterns of Social Care in Five Industrial Societies: Explaining Diversity. In A. Anttonen, J. Baldock, & J. Sipilä, eds. *The Young, the Old and the State*. Cheltenham, London: Edward Elgar, pp. 167–198.
- Appleby, J., Harrison, A. & Devlin, N., 2003. *What is the real cost of more patient choice*, London: King’s Fund Publishing.
- Arksey, H. & Baxter, K., 2012. Exploring the Temporal Aspects of Direct Payments. *British Journal of Social Work*, 42, pp.147–164.
- Arksey, H. & Glendinning, C., 2008. Combining work and care: carers’ decision-making in the context of competing policy pressures. *Social Policy & Administration*, 42(1), pp.1–18.
- Arrow, K.J., 1972. Gifts and Exchanges. *Philosophy and Public Affairs*, 1(4), pp.343–362.
- Arrow, K.J., 1963. Uncertainty and the Welfare Economics of Medical Care. *The American Economic Review*, 53(5), pp.941–973.
- Audit Commission, 1986. *Making a Reality of Community Care*, London: Her Majesty’s Stationery Office.
- Baalen, A. van, Vingerhoets, A., Sixma, H. & de Lange, J., 2011. How to evaluate quality of care from the perspective of people with dementia: an overview of the literature. *Dementia*, 10(1), pp.112–137.
- Baldock, J., 1997. Social Care in Old Age: More Than a Funding Problem. *Social Policy & Administration*, 31(1), pp.73–89.

- Barr, N., 2004. *Economics of the Welfare State*, Oxford: Oxford University Press.
- Bartlett, W. & Le Grand, J., 1993. The theory of quasi-markets. In J. Le Grand & W. Bartlett, eds. *Quasi-markets and social policy*. Basingstoke: Macmillan Press, pp. 13–34.
- Baumol, W.J., 1967. Macroeconomics of unbalanced growth: the anatomy of urban crisis. *The American Economic Review*, 57(3), pp.415–426.
- Baumol, W.J. & Bowen, W.G., 1965. On the Performing Arts: The Anatomy of Their Economic Problems. *The American Economic Review*, 55(1/2), pp.495–502.
- Baxter, K. & Glendinning, C., 2013. The role of emotions in the process of making choices about welfare services: the experiences of disabled people in England. *Social Policy and Society*, 12(3), pp.439–450.
- Baxter, K., Glendinning, C. & Clarke, S., 2008. Making informed choices in social care: the importance of accessible information. *Health & Social Care in the Community*, 16(2), pp.197–207.
- Baxter, K., Glendinning, C. & Greener, I., 2011. The implications of personal budgets for the home care market. *Public Money & Management*, 31(2), pp.91–98.
- Baxter, K., Rabiee, P. & Glendinning, C., 2013. Managed personal budgets for older people: what are English local authorities doing to facilitate personalized and flexible care? *Public Money & Management*, 33(6), pp.399–406.
- Bechhofer, F. & Paterson, L., 2000. *Principles of Research Design in the Social Sciences*, London: Routledge.
- Becker, G., 1965. A Theory of the Allocation of Time. *The Economic Journal*, 75(299), pp.493–517.
- Becker, G., 1976. *The economic approach to human behavior*, Chicago, London: University of Chicago Press.
- Beresford, B. & Sloper, P., 2008. *Understanding the Dynamics of Decision-Making and Choice: A scoping study of key psychological theories to inform the design and analysis of the Panel Study*, York: Social Policy Research Unit, University of York.
- Besley, T., 2013. What's the Good of the Market? An Essay on Michael Sandel's What Money Can't Buy. *Journal of Economic Literature*, 51(2), pp.478–495.
- Black, J., Hashimzade, N. & Myles, G., 2009. *Oxford Dictionary of Economics*, New York NY: Oxford University Press. Available at: <http://www.oxfordreference.com/view/10.1093/acref/9780199237043.001.0001/acref-9780199237043>.
- Blomqvist, P., 2004. The Choice Revolution: Privatization of Swedish Welfare Services in the 1990s. *Social Policy & Administration*, 38(2), pp.139–155.

- Bode, I., Gardin, L. & Nyssens, M., 2011. Quasi-marketisation in domiciliary care: varied patterns, similar problems? *International Journal of Sociology and Social Policy*, 31(3/4), pp.222–235.
- Bowden, P., 1997. *Caring. Gender-Sensitive Ethics*, London: Routledge.
- Bowen, G., 2008. Naturalistic inquiry and the saturation concept: a research note. *Qualitative Research*, 8(1), pp.137–152.
- Bowles, S., 1998. Endogenous Preferences : The Cultural Consequences of Markets and other Economic Institutions. *Journal of Economic Literature*, 36(1), pp.75–111.
- Boyle, G., 2005. The role of autonomy in explaining mental ill-health and depression among older people in long-term care settings. *Ageing & Society*, 25(5), pp.731–748.
- Bradley, E.H., Curry, L.A. & Devers, K.J., 2007. Qualitative Data Analysis for Health Services Research: Developing Taxonomy, Themes, and Theory. *Health Services Research*, 42(4), pp.1758–1772.
- Bradshaw, J.R., 1972. The taxonomy of social need. In G. McLachlan, ed. *Problems and Progress in Medical Care*. Oxford: Oxford University Press, pp. 69–82.
- Caplow, T., 1982. Christmas gifts and kin networks. *American Sociological Review*, 47(3), pp.383–392.
- Care Quality Commission, 2011. *The state of health care and adult social care in England*, London: The Stationery Office.
- Carr, S., 2012. *Personalisation : a rough guide*, London: Social Care Institute for Excellence.
- Carstensen, L.L., 1995. Evidence for a life span theory of socioemotional selectivity. *Current Directions in Psychological Science*, 4(5), pp.151–156.
- Carstensen, L.L., Isaacowitz, D.M. & Charles, S.T., 1999. Taking time seriously: A theory of socioemotional selectivity. *American Psychologist*, 54(3), pp.165–181.
- Challis, D. & Davies, B., 1986. *Case Management in Community Care: An Evaluated Experiment in the Home Care of the Elderly*, Aldershot: Gower.
- Clare, L., Woods, R.T., Nelis, S.M. et al., 2014. Trajectories of quality of life in early-stage dementia: individual variations and predictors of change. *International Journal of Geriatric Psychiatry*, 29(6), pp.616–623.
- Clark, H., Gough, H. & McFarlane, A., 2004. *It Pays Dividends': Direct Payments and Older people*, Bristol: Policy Press, Joseph Rowntree Foundation.
- Clarke, J., 2006. Consumers, Clients or Citizens? Politics, Policy and Practice in the Reform of Social Care. *European Societies*, 8(3), pp.423–442.
- Clarke, J., Newman, J. & Westmarland, L., 2007. The Antagonisms of Choice: New Labour and the reform of public services. *Social Policy and Society*, 7(02), pp.245–253.

- Clarke, J., Smith, N. & Vidler, E., 2005. Consumerism and the reform of public services; inequalities and instabilities. In M. Powell, K. Clarke, & L. Bauld, eds. *Social Policy Review 17: Analysis and Debates in Social Policy*. Bristol: Policy Press, pp. 167–182.
- Clarke, J., Smith, N. & Vidler, E., 2006. The Indeterminacy of Choice: Political, Policy and Organisational Implications. *Social Policy and Society*, 5(03), pp.327–336.
- Collopy, B.J., 1995. Power, paternalism and the ambiguities of autonomy. In L. M. Gamroth, J. Semradek, & E. M. Tornquist, eds. *Enhancing Autonomy in Long-Term Care. Concepts and Strategies*. New York NY: Springer Publishing Company, pp. 3–14.
- Colombo, F., Llena-Nozal, A., Mercier, J. & Tjadens, F., 2011. *Help wanted? Providing and paying for long-term care*, Paris: OECD Publishing.
- Cullis, J.C. & Jones, P.R., 2009. *Public finance and public choice: analytical perspectives* 3rd ed., Oxford: Oxford University Press.
- Culyer, A.J., 2007. Need: An Instrumental View. In R. E. Ashcroft et al., eds. *Principles of Health Care Ethics*. Chichester: John Wiley & Sons., pp. 231–238.
- Daly, M. & Lewis, J., 2000. The concept of social care and the analysis of contemporary welfare states. *The British journal of sociology*, 51(2), pp.281–98.
- Davey, V., Fernández, J. L., Knapp, M. et al., 2007. *Direct Payments: A National Survey of Direct Payments Policy and Practice*, London: Personal Social Services Research Unit.
- Davies, B. & Knapp, M., 1981. *Old people's homes and the production of welfare*, London, Boston: Routledge & Kegan Paul.
- Davies, S., 2001. The Care Needs of Older People and Family Caregivers in Continuing Care Settings. In M. Nolan, S. Davies, & G. Grant, eds. *Working with Older People and Their Families*. Buckingham: Open University Press, pp. 75–98.
- Dawson, C., 2000. *Independent Successes: Implementing Direct Payments*, York: Joseph Rowntree Foundation.
- Department of Health, 2005. *Independence, Well-being and Choice*, London: Her Majesty's Stationery Office.
- Dorman, P., Folbre, N., McCloskey, D. & Weisskopf, T., 1996. Debating Markets. *Feminist Economics*, 2(1), pp.69–85.
- Dowding, K. & John, P., 2009. The Value of Choice in Public Policy. *Public Administration*, 87(2), pp.219–233.
- Doyal, L. & Gough, I., 1991. *A Theory of Human Need*, Basingstoke: Palgrave Macmillan.
- Duffy, S., 2004. In control. *Journal of Integrated Care*, 12(6), pp.7–13.
- Eales, J., Keating, N. & Damsma, A., 2001. Seniors' experiences of client-centred residential care. *Ageing & Society*, 21(03), pp.279–296.

- Edebalk, P.G., Samuelsson, G. & Ingvad, B., 1995. How Elderly People Rank-Order the Quality Characteristics of Home Services. *Ageing & Society*, 15, pp.83–102.
- Egger de Campo, M., 2007. Exit and voice: an investigation of care service users in Austria, Belgium, Italy, and Northern Ireland. *European Journal of Ageing*, 4(2), pp.59–69.
- Eichler, M. & Pfau-Effinger, B., 2009. The “Consumer Principle” in the Care of Elderly People: Free Choice and Actual Choice in the German Welfare State. *Social Policy & Administration*, 43(6), pp.617–633.
- Eika, K.H., 2009. The Challenge of Obtaining Quality Care: Limited Consumer Sovereignty in Human Services. *Feminist Economics*, 15(1), pp.113–137.
- Ellis, K., 2007. Direct Payments and Social Work Practice: The Significance of “Street-Level Bureaucracy” in Determining Eligibility. *British Journal of Social Work*, 37(3), pp.405–422.
- England, P., 2005. Emerging Theories of Care Work. *Annual Review of Sociology*, 31, pp.381–399.
- England, P. & Folbre, N., 2003. Contracting for care. In M. Ferber & J. Nelson, eds. *Feminist Economics Today*. Chicago: University of Chicago Press, pp. 61–80.
- Ettema, T., Dröes, R., de Lange, J., Mellenbergh, G. & Ribbe, M., 2005. A review of quality of life instruments used in dementia. *Quality of Life Research*, 14(3), pp.675–686.
- Eustis, N.N. & Fischer, L.R., 1991. Relationships between home care clients and their workers: implications for quality of care. *The Gerontologist*, 31(4), pp.447–456.
- Fereday, J. & Muir-Cochrane, E., 2006. Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods*, 5(1), pp.1–11.
- Fernández, J.L., Kendall, J., Davey, V. & Knapp, M., 2007. Direct Payments in England: Factors Linked to Variations in Local Provision. *Journal of Social Policy*, 36(1), pp.97–121.
- Fernández, J.L. & Forder, J., 2011. Equity, efficiency, and financial risk of alternative arrangements for funding long-term care systems in an ageing society. *Oxford Review of Economic Policy*, 26(4), pp.713–733.
- Fine, M.D., 2007. *A Caring Society? Care and the Dilemmas of Human Service in the 21st Century*, Basingstoke: Palgrave Macmillan.
- Fine, M.D. & Glendinning, C., 2005. Dependence, independence or inter-dependence? Revisiting the concepts of “care” and “dependency.” *Ageing & Society*, 25(4), pp.601–621.
- Folbre, N., 1995. “Holding hands at midnight”: the paradox of caring labor. *Feminist Economics*, 1(1), pp.73–92.
- Folbre, N., 2008. Reforming Care. *Politics & Society*, 36(3), pp.373–387.

- Folbre, N. & Nelson, J.A., 2000. For Love or Money-Or Both ? *Journal of Economic Perspectives*, 14(4), pp.123–140.
- Folbre, N. & Weisskopf, T., 1998. Did father know best? Families, markets and the supply of caring labor. In A. Ben-Ner & L. Putterman, eds. *Economics, Values, and Organization*. Cambridge, UK: Cambridge University Press, pp. 171–205.
- Forder, J., Knapp, M., Hardy, B., Kendall, J., Matosevic, T. & Ware, P., 2004. Prices, contracts and motivations: institutional arrangements in domiciliary care. *Policy & Politics*, 32(2), pp.207–222.
- Forder, J., Knapp, M. & Wistow, G., 1996. Competition in the Mixed Economy of Care. *Journal of Social Policy*, 25(2), pp.201–221.
- Fotaki, M., Boyd, A., Smith, L. et al., 2005. *Patient Choice and the Organisation and Delivery of Health Services: Scoping review*, Manchester: Centre for Public Policy and Management, Manchester Business School, University of Manchester.
- Frey, B.S., 1998. Institutions and morale: the crowding-out effect. In A. Ben-Ner & L. Putterman, eds. *Economics, Values, and Organization*. Cambridge, UK: Cambridge University Press, pp. 437–460.
- Gibson, D.M., 1985. The Dormouse Syndrome - Restructuring the Dependency of the Elderly. *Journal of Sociology*, 21(1), pp.44–63.
- Giddens, A., 1994. *Beyond Left and Right*, Cambridge: Polity Press.
- Gilligan, C., 1993. *In a Different Voice: Psychological Theory and Women's Development*, Cambridge, MA: Harvard University Press.
- Glasby, J. & Littlechild, R., 2009. *Direct Payments and Personal Budgets: Putting Personalisation Into Practice*, Bristol: Policy Press.
- Glendinning, C., Challis, D., Fernández, J. L. et al., 2008. *Evaluation of the Individual Budgets Pilot Programme Final Report*, York: Social Policy Research Unit, University of York.
- Glendinning, C., 2012. Home care in England: markets in the context of under-funding. *Health & Social Care in the Community*, 20(3), pp.292–299.
- Glendinning, C., 2008. Increasing Choice and Control for Older and Disabled People: A Critical Review of New Developments in England. *Social Policy & Administration*, 42(5), pp.451–469.
- Glendinning, C., Rummery, K., Halliwell, S., Jacobs, S. & Tyrer, J., 2000. *Buying Independence: Using Direct Payments to Purchase Integrated Health and Social Services*, Bristol: Policy Press.
- Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K. & Tyrer, J., 2000. New kinds of care, new kinds of relationships: how purchasing services affects relationships in giving and receiving personal assistance. *Health & Social Care in the Community*, 8(3), pp.201–211.

- Glendinning, C. & Kemp, P.A. eds., 2006. *Cash and Care: Policy challenges in the welfare state*, Bristol: Policy Press.
- Graham, H., 1983. Caring: a Labor of Love. In J. Finch & D. Groves, eds. *A Labor of Love: Women, Work and Caring*. London, Boston: Routledge and Kegan Paul, pp. 13–30.
- Le Grand, J., 2006. Equality and Choice in Public Services. *Social Research*, 73(2), pp.695–710.
- Le Grand, J., 1997. Knights, Knaves or Pawns? Human Behaviour and Social Policy. *Journal of Social Policy*, 26(2), pp.149–169.
- Le Grand, J., 2003. *Motivation, agency and public policy: of knights and knaves, pawns and queens*, Oxford: Oxford University Press.
- Le Grand, J., 1991a. Quasi-markets and social policy. *The Economic Journal*, 101, pp.1256–1267.
- Le Grand, J., 2007. *The other invisible hand: delivering public services through choice and competition*, Princeton NJ: Princeton University Press.
- Le Grand, J., 1991b. The Theory of Government Failure. *British Journal of Political Science*, 21(4), pp.423–442.
- Le Grand, J. & Bartlett, W., 1993. Quasi-markets and social policy: the way forward? In J. Le Grand & W. Bartlett, eds. *Quasi-Markets and Social Policy*. Basingstoke: Macmillan, pp. 202–220.
- Le Grand, J., Propper, C. & Robinson, R., 1992. *The Economics of Social Problems* 3rd ed., Basingstoke: Macmillan.
- Granovetter, M., 1985. Economic-Action and Social-Structure - the Problem of Embeddedness. *American Journal of Sociology*, 91(3), pp.481–510.
- Green, J., 2006. Patient choice: as attractive as it seems? A sociological perspective. *Journal of Health Services Research and Policy*, 11(3), pp.131–132.
- Greener, I., 2007. Are the assumptions underlying patients choice realistic?: a review of the evidence. *British Medical Bulletin*, 83, pp.249–258.
- Greener, I. & Mannion, R., 2009. Patient choice in the NHS: what is the effect of choice policies on patients and relationships in health economies? *Public Money & Management*, 29(2), pp.95–100.
- Greve, B., 2009. Can Choice in Welfare States Be Equitable? *Social Policy & Administration*, 43(6), pp.543–556.
- Griffiths, R., 1988. *Community Care: Agenda for Action - A Report to the Secretary of State for Social Services*, London: Her Majesty's Stationery Office.
- Guest, G., Bunce, A. & Johnson, L., 2006. How Many Interviews Are Enough? An Experiment with Data Saturation and Variability. *Field Methods*, 18(1), pp.59–82.

- Hancock, R., Wittenberg, R., Hu, B., Morciano, M. & Comas-Herrera, A., 2013. *Long-term care funding in England: an analysis of the costs and distributional effects of potential reforms*, Canterbury, London.
- Hardy, B. & Wistow, G., 1998. Securing Quality through Contracts? The Development of Quasi-Markets for Social Care in Britain. *Australian Journal of Public Administration*, 57(2), pp.25–35.
- Hardy, B., Young, R. & Wistow, G., 1999. Dimensions of choice in the assessment and care management process: the views of older people, carers and care managers. *Health & Social Care in the Community*, 7(6), pp.483–491.
- Hatton, C. & Waters, J., 2011. *The national personal budget survey*, In Control, Lancaster University.
- Head, J.G., 1988. On Merit Wants: Reflections on the Evolution, Normative Status and Policy Relevance of a Controversial Public Finance Concept G. Walsh & C. Brennan, eds. *FinanzArchiv / Public Finance Analysis*, 46(H 1), pp.1–37.
- Held, V., 2002. Care and the extension of the market. *Hypatia*, 17(2), pp.19–33.
- Henwood, M. & Hudson, B., 2007. *Review of the Independent Living Funds*, London: Department of Work and Pensions.
- Heyes, A., 2005. The economics of vocation or “why is a badly paid nurse a good nurse”? *Journal of health economics*, 24(3), pp.561–569.
- Higgs, P., Hyde, M., Wiggins, R. & Blane, D., 2003. Researching Quality of Life in Early Old Age: the Importance of the Sociological Dimension. *Social Policy & Administration*, 37(3), pp.239–252.
- Himmelweit, S., 1999. Caring Labor. *Annals of the American Academy of Political and Social Science*, 561, pp.27–38.
- Himmelweit, S., 2007. The prospects for caring: economic theory and policy analysis. *Cambridge Journal of Economics*, 31, pp.581–599.
- Hirschmann, A., 1970. *Exit, voice and loyalty: Responses to Decline in Firms, Organizations, and State*, Cambridge MA: Harvard University Press.
- Hochschild, A.R., 1983. *The Managed Heart: Commercialization of Human Feeling*, Berkeley, CA: University of California Press.
- Hodgson, G., 2008. An institutional and evolutionary perspective on health economics. *Cambridge Journal of Economics*, 32(2), pp.235–256.
- Hood, C., 1991. A Public Management for All Seasons? *Public Administration*, 69, pp.3–19.
- Hsieh, H.-F. & Shannon, S.E., 2005. Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), pp.1277–1288.

- Hurley, J., 2000. An overview of the normative economics of the health sector. In J. Anthony & J. P. Newhouse, eds. *Handbook of Health Economics*. Amsterdam: North Holland, pp. 55–118.
- Ipsos MORIS, 2011. *Users of Social Care Personal Budgets*, London: Ipsos MORI.
- Jacobs, S., Xie, C., Reilly, S., Hughes, J. & Challis, D., 2009. Modernising social care services for older people: scoping the United Kingdom evidence base. *Ageing & Society*, 29, pp.497–538.
- Jochimsen, M.A., 2003. *Careful Economics. Integrating Caring Activities and Economic Science*, Dordrecht: Kluwer Academic Publishers.
- Jones, K., Netten, A., Fernández, J. L. et al., 2012. The impact of individual budgets on the targeting of support: findings from a national evaluation of pilot projects in England. *Public Money & Management*, 32(6), pp.417–424.
- Jones, P. & Cullis, J., 2000. “Individual Failure” and the Analytics of Social Policy. *Journal of Social Policy*, 29(1), pp.73–93.
- Jones, P. & Cullis, J., 2002. Merit Want Status and Motivation: The Knight Meets the Self-Loving Butcher, Brewer, and Baker. *Public Finance Review*, 30(2), pp.83–101.
- Jordan, B., 2005. Public Services and the Service Economy: Individualism and the Choice Agenda. *Journal of Social Policy*, 35(01), pp.143–162.
- Kahneman, D. & Tversky, A., 1979. Prospect Theory: An Analysis of Decision under Risk. *Econometrica*, 47(2), pp.263–292.
- Kane, R. a, 2003. Definition, measurement, and correlates of quality of life in nursing homes: toward a reasonable practice, research, and policy agenda. *The Gerontologist*, 43(Special Issue II), pp.28–36.
- Kaye, S., 2007. Inclusion of People with Disabilities in the NHIS and NHIS-D: Non-Response, Proxy Response, and Assisted Response. In T. Kroll et al., eds. *Towards Best Practices for Surveying People with Disabilities, vol. 1*. New York, NY: Nova Publishers, pp. 105–125.
- Kestenbaum, A., 1992. Cash for Care: A Report on the Experience of Independent Living Fund Clients. In Nottingham: Independent Living Fund.
- Kestenbaum, A., 1993. *Making Community Care a Reality*, Nottingham: Independent Living Fund.
- Kittay, E.F., 1999. *Love’s Labor. Essays on Women, Equality and Dependency*, New York NY: Routledge.
- Klein, R. & Millar, J., 1995. Do-It-Yourself Social Policy: Searching for a New Paradigm? *Social Policy & Administration*, 29(4), pp.303–316.
- Knapp, M., Wistow, G., Forder, J. & Hardy, B., 1994. Markets for social care: opportunities, barrier and implications. In W. Bartlett et al., eds. *Quasi-Markets in the Welfare State*. Bristol: SAUS, pp. 123–157.

- Knapp, M., 1984. *The Economics of Social Care*, Basingstoke: MacMillan.
- Knapp, M., Hardy, B. & Forder, J., 2001. Commissioning for Quality: Ten Years of Social Care Markets in England. *Journal of Social Policy*, 30(02), pp.283–306.
- Knijjn, T. & Kremer, M., 1997. Gender and the Caring Dimension of Welfare States: Towards Inclusive Citizenship. *Social Politics*, 4(3), pp.328–361.
- Kremer, M., 2006. Consumers in Charge of Care: the Dutch Personal Budget and Its Impact on the Market, Professionals and the Family. *European Societies*, 8(3), pp.385–401.
- Kröger, T., 2009. Care research and disability studies: Nothing in common? *Critical Social Policy*, 29, pp.398–420.
- Lancaster, K., 1966. A New Approach to Consumer Theory. *Journal of Political Economy*, 74(2), pp.132–157.
- Leadbetter, C., 2004. *Personalisation through Participation: A New Script for Public Services*, London: Demos.
- Lee, S., Mathiowetz, N. & Tourangeau, R., 2004. Perceptions of Disability: The Effect of Self- and Proxy Response. *Journal of Official Statistics*, 20(4), pp.671–686.
- Leece, J., 2010. Paying the Piper and Calling the Tune: Power and the Direct Payment Relationship. *British Journal of Social Work*, 40, pp.188–206.
- Leira, A., 1994. Concepts of Caring: Loving, Thinking, and Doing. *Social Service Review*, 68(2), pp.185–201.
- Lerner, J.S. & Keltner, D., 2000. Beyond valence: toward a model of emotion-specific influences on judgement and choice. *Cognition and Emotion*, 14, pp.473–493.
- Lewinter, M., 2003. Reciprocities in caregiving relationships in Danish elder care. *Journal of Aging Studies*, 17, pp.357–377.
- Lewis, J., 2003. Design Issues. In J. Ritchie & J. Lewis, eds. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London, Thousand Oaks CA, New Delhi: Sage Publications, pp. 47–76.
- Lewis, J. & Glennerster, H., 1996. *Implementing the new community care*, Philadelphia PA: Open University Press.
- Lewis, J. & Ritchie, J., 2003. Generalising from Qualitative Research. In J. Ritchie & J. Lewis, eds. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London, Thousand Oaks CA, New Delhi: Sage Publications, pp. 263–286.
- Lewis, J. & West, A., 2014. Re-shaping social care services for older people in England: policy development and the problem of achieving “good care.” *Journal of Social Policy*, 43(01), pp.1–18.

- Lundsgaard, J., 2005. *Consumer Direction and Choice in Long-Term Care for Older Persons, Including Payments for Informal Care - How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability?*, Paris: OECD Working Papers 20.
- Lunt, N., Mannion, R. & Smith, P., 1996. Economic Discourse and the Market: The Case of Community Care. *Public Administration*, 74(3), pp.369–391.
- Mannion, R. & Smith, P., 1997. How purchasing decisions are made in the mixed economy of community care. *Financial Accountability & Management*, 13(3), pp.243–260.
- Manthorpe, J., Hindes, J., Martineau, S. et al., 2011. *Self-Directed Support: A Review of the Barriers and Facilitators*, Edinburgh: Scottish Government Social Research.
- Marshall, M.N., 1996. Sampling for qualitative research. *Family Practice*, 13(6), pp.522–525.
- Marshall, T.H., 1963. *Sociology at the Crossroads and Other Essays*, London: Heinemann.
- Mauss, M., 1954. *The gift: Forms and Functions of Exchanges in Archaic Societies*, London: Cohen and West.
- Means, R., 2012. A Brave New World of Personalized Care? Historical Perspectives on Social Care and Older People in England. *Social Policy & Administration*, 46(3), pp.302–320.
- Miles, M.B. & Huberman, A.M., 1994. *Qualitative Data Analysis: An Expanded Sourcebook*, London: Sage Publications.
- Moran, N., Glendinning, C., Stevens, M. et al., 2011. Joining Up Government by Integrating Funding Streams? The Experiences of the Individual Budget Pilot Projects for Older and Disabled People in England. *International Journal of Public Administration*, 34(4), pp.232–243.
- Moran, N., Glendinning, C., Wilberforce, M. et al., 2013. Older people's experiences of cash-for-care schemes: evidence from the English Individual Budget pilot projects. *Ageing & Society*, 33(05), pp.826–851.
- Morris, J., 1994. Community care or independent living? *Critical Social Policy*, 14, pp.24–45.
- Morris, J., 2006. Independent living: the role of the disability movement in the development of government policy. In C. Glendinning & P. A. Kemp, eds. *Cash and Care: Policy Challenges in the Welfare State*. Bristol: Policy Press, pp. 235–248.
- Mueller, D.C., 2003. *Public Choice III*, Cambridge, New York NY: Cambridge University Press.
- National Audit Office, 2011. *Oversight of user choice and provider competition in care markets*, London: The Stationery Office.
- National Care Homes Research and Development, 2007. *My Home Life: Quality of Life in Care Homes: A Review of the Literature*, London: Help the Aged.
- Needham, C., 2006. Customer Care and the Public Service Ethos. *Public Administration*, 84(4), pp.845–860.

- Needham, C., 2011. Personalization: From Story-line to Practice. *Social Policy & Administration*, 45(1), pp.54–68.
- Needham, C., 2013. Personalized commissioning, public spaces: the limits of the market in English social care services. *BMC Health Services Research*, 13(Suppl 1), p.S5.
- Nelis, S.M., Clare, L. & Whitaker, C.J., 2012. Attachment representations in people with dementia and their carers: implications for well-being within the dyad. *Aging & Mental Health*, 16(7), pp.845–854.
- Nelson, J., 1999. Of markets and martyrs: Is it OK to pay well for care? *Feminist Economics*, 5(3), pp.43–59.
- Nelson, P., 1970. Information and Consumer Behavior. *Journal of Political Economy*, 78(2), pp.311–329.
- Netten, A., Jones, K., Knapp, M. et al., 2012. Personalisation through Individual Budgets: Does It Work and for Whom? *British Journal of Social Work*, 42, pp.1556–1573.
- Netten, A. & Davies, B., 1990. The Social Production of Welfare and Consumption of Social Services. *Journal of Public Policy*, 10(3), pp.331–347.
- New, B., 1999. Paternalism and Public Policy. *Economics and Philosophy*, 15(1), pp.63–83.
- Newbrunner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B. & Glendinning, C., 2011. *Keeping personal budgets personal : learning from the experiences of older people , people with mental health problems and their carers*, London: Social Care Institute for Excellence.
- NHS, 2014. NASCIS Database. Available at:
<https://login.hscic.gov.uk/Login.aspx?version=4&referrer=http%253a%252f%252fnascis.hscic.gov.uk%252fDefault.aspx&info=http%253a%252f%252fnascis.hscic.gov.uk%253a80%252fSignIn.htm>.
- NHS, 2013. NASCIS Database. Available at:
<https://login.hscic.gov.uk/Login.aspx?version=4&referrer=http%3a%2f%2fnascis.hscic.gov.uk%2fDefault.aspx&info=http%3a%2f%2fnascis.hscic.gov.uk%3a80%2fSignIn.htm>.
- NHS Information Centre, 2006. *Community Care Statistics 2005 - Home care services for adults, England*, Health and Social Care Information Centre.
- NHS Information Centre, 2009. *Community Care Statistics 2008 - Home care services for adults, England*, Health and Social Care Information Centre.
- Nolan, M., Brown, J., Davies, S., Nolan, J. & Keady, J., 2006. *The Senses Framework: Improving care for older people through a relationship-centred approach. Getting Research into Practice (GRiP) Report No. 2 Project Report.*, Sheffield: University of Sheffield.
- Norton, E.C., 2000. Long-term care. In A. J. Culyer & J. P. Newhouse, eds. *Handbook of Health Economics, Volume 1*. Amsterdam, Lausanne, New York NY, Oxford, Shannon, Singapore, Tokyo: Elsevier Science B.V., pp. 956–994.

- O'Reilly, M. & Parker, N., 2013. "Unsatisfactory Saturation": a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, 13(2), pp.190–197.
- OECD, 2005. *Long-Term Care for Older People*, Paris: OECD.
- Office of National Statistics, 2014a. Census 2011 for England and Wales. Available at: <http://www.ons.gov.uk/ons/guide-method/census/2011/census-data/index.html>.
- Office of National Statistics, 2014b. Disability-free life expectancy (DFLE) and life expectancy (LE) at birth, from age 50 and age 65: England 2010-12. Available at: <http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Disability-free+Life+Expectancy#tab-data-tables>.
- Oliver, A. & Evans, J.G., 2005. The paradox of promoting choice in a collectivist system. *Journal of Medical Ethics*, 31(4), p.187.
- Olsson, E. & Ingvad, B., 2001. The emotional climate of care-giving in home-care services. *Health & Social Care in the Community*, 9(6), pp.454–463.
- Parker, G. & Clarke, H., 1997. Will you still need me? Will you still feed me? - Paying for Care in Old Age. *Social Policy & Administration*, 31(2), pp.119–135.
- Patton, M.Q., 2002. *Qualitative Research and Evaluation Methods* 3rd ed., Thousand Oaks CA: Sage Publications.
- Pavolini, E. & Ranci, C., 2008. Restructuring the welfare state: reforms in long-term care in Western European countries. *Journal of European Social Policy*, 18(3), pp.246–259.
- Piercy, K.W., 2000. When It Is More Than a Job: Close Relationships between Home Health Aides and Older Clients. *Journal of Aging and Health*, 12(3), pp.362–387.
- Poll, C., Duffy, S., Hatton, C., Sanderson, H. & Routledge, M., 2006. *A Report on In Control's First Phase 2003-2005*, London: In Control Publications.
- Powell, M., Greener, I., Szmigin, I., Doheny, S. & Mills, N., 2010. Broadening the Focus of Public Service Consumerism. *Public Management Review*, 12(3), pp.323–339.
- Priestley, M., Jolly, D., Pearson, C., Ridell, S., Barnes, C. & Mercer, G., 2007. Direct Payments and Disabled People in the UK: Supply, Demand and Devolution. *British Journal of Social Work*, 37, pp.1189–1204.
- Prime Minister's Strategy Unit, 2005. *Improving the Life Chances of Disabled People*, London: Cabinet Office.
- Qazi, A., Spector, A. & Orrell, M., 2010. User, carer and staff perspectives on anxiety in dementia: A qualitative study. *Journal of Affective Disorders*, 125, pp.295–300.
- Rabiee, P., 2013. Exploring the Relationships between Choice and Independence : Experiences of Disabled and Older People. *British Journal of Social Work*, 43, pp.872–888.

- Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestley, M. & Mercer, G., 2005. The Development of Direct Payments in the UK: Implications for Social Justice. *Social Policy and Society*, 4(1), pp.75–85.
- Ritchie, J., 2003. The Applications of Qualitative Methods to Social Research. In J. Ritchie & J. Lewis, eds. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London, Thousand Oaks CA, New Delhi: Sage Publications, pp. 24–46.
- Ritchie, J. & Lewis, J. eds., 2003. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, London, Thousand Oaks CA, New Delhi: Sage Publications.
- Ritchie, J., Lewis, J. & Elam, G., 2003. Designing and Selecting Samples. In J. Ritchie & J. Lewis, eds. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London, Thousand Oaks CA, New Delhi: Sage Publications, pp. 77–108.
- Ritchie, J., Spencer, L. & O'Connor, W., 2003. Carrying out Qualitative Analysis. In J. Ritchie & J. Lewis, eds. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London, Thousand Oaks CA, New Delhi: Sage Publications, pp. 219–262.
- Robson, W., 1976. *Welfare State and Welfare Society*, London: Allen & Unwin.
- Rodrigues, R., Trigg, L., Schmidt, A. & Leichsenring, K., 2014. The public gets what the public wants: experiences of public reporting in long-term care in Europe. *Health Policy*, 116(1), pp.84–94.
- Da Roit, B. & Le Bihan, B., 2010. Similar and Yet so Different: Cash-for-Care in Six European Countries' Long-term Care Policies. *Milbank Quarterly*, 88(3), pp.286–309.
- Da Roit, B., Le Bihan, B. & Österle, A., 2007. Long-term Care Policies in Italy, Austria and France: Variations in Cash-for-Care Schemes. *Social Policy & Administration*, 41(6), pp.653–671.
- Roth, A.E., 2007. Repugnance as a Constraint on Markets. *Journal of Economic Perspectives*, 21(3), pp.37–58.
- Rothgang, H. & Igl, G., 2007. Long-term Care in Germany. *The Japanese Journal of Social Security*, 6(1), pp.54–84.
- Rothschild, M. & Stiglitz, J.E., 1976. Equilibrium in Competitive Insurance Markets: An Essay on the Economics of Imperfect Information. *Quarterly Journal of Economics*, 90(4), pp.629–649.
- Routledge, M. & Lewis, J., 2011. *Personal Budgets: taking stock, moving forward*, London: Think Local, Act Personal Partnership.
- Sandel, M.J., 2013. Market Reasoning as Moral Reasoning : Why Economists Should Re-engage with Political Philosophy. *Journal of Economic Perspectives*, 27(4), pp.121–140.
- Sandel, M.J., 2012. *What Money Can't Buy: The Moral Limits of Markets*, New York NY: Farrar, Straus and Giroux.
- Schwartz, B., 2004. *The Paradox of Choice: Why More is Less*, New York NY: Harper Books.

- Scourfield, P., 2007. Are there reasons to be worried about the “cartelization” of residential care? *Critical Social Policy*, 27(2), pp.155–180.
- Scourfield, P., 2005. Implementing the Community Care (Direct Payments) Act: Will the Supply of Personal Assistants meet the Demand and at what Price? *Journal of Social Policy*, 34(3), pp.469–488.
- Sen, A., 1997. *Choice, Welfare and Measurement* 2nd ed., Cambridge MA: Harvard University Press.
- Sen, A., 1977. Rational Fools: A Critique of the Behavioural Foundations of Economic Theory. *Philosophy & Public Affairs*, 6(4), pp.317–344.
- Sevenhuijsen, S., 1998. *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics*, London and New York NY: Routledge.
- Sheikh, S., Vanson, T., Comber, N. & Watts, R., 2012. *Longitudinal study of Personal Budgets for Adult Social Care in Essex – Round three final report*, London: Office for Public Management.
- Simon, H.A., 1957. *Administrative Behaviour*, New York NY: Free Press.
- Smith, A., 1776. *An inquiry into the nature and causes of the wealth of nations. Vol. 1.* 1910 Repr., New York NY: Pluto.
- Smith, C., Preston-Shoot, M. & Buckley, J., 1995. *Community Care Reforms: The Views of Users and Carers*, Manchester: Department of Social Policy and Social Work, University of Manchester, Working Paper 8.
- Snape, D. & Spencer, L., 2003. The Foundations of Qualitative Research. In J. Ritchie & J. Lewis, eds. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London, Thousand Oaks CA, New Delhi: Sage Publications, pp. 1–23.
- Spandler, H. & Vick, N., 2005. Enabling access to direct payments: An exploration of care co-ordinators decision-making practices. *Journal of Mental Health*, 14(2), pp.145–155.
- Spencer, L., Ritchie, J. & O’Connor, W., 2003. Analysis, Practices, Principles and Processes. In J. Ritchie & J. Lewis, eds. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London, Thousand Oaks CA, New Delhi: Sage Publications, pp. 199–218.
- Stainton, T. & Boyce, S., 2004. “I have got my life back”: users’ experience of direct payments. *Disability & Society*, 19(5), pp.443–454.
- Stevens, M., Glendinning, C., Jacobs, S. et al., 2011. Assessing the Role of Increasing Choice in English Social Care Services. *Journal of Social Policy*, 40(02), pp.257–274.
- Stiglitz, J.E., 2000. *Economics of the Public Sector* 3rd ed., New York NY: W. W. Norton.
- Taylor-Gooby, P., 1998. Choice and the Policy Agenda. In P. Taylor-Gooby, ed. *Choice and public policy: the limits of welfare markets*. Basingstoke: Palgrave Macmillan, pp. 1–23.

- Taylor-Gooby, P., 2008. Choice and Values: Individualised Rational Action and Social Goals. *Journal of Social Policy*, 37(02), pp.167–185.
- Taylor-Gooby, P., 1999. Markets and Motives Trust and Egoism in Welfare Markets. *Journal of Social Policy*, 28(1), pp.97–114.
- Taylor-Gooby, P. & Lawson, R., 1993. *Markets and Managers: New Issues in the Delivery of Welfare*, Milton Keynes: Open University Press.
- Thaler, R.H., 1980. Toward a positive theory of consumer choice. *Journal of Economic Behavior and Organization*, 1, pp.39–60.
- Timonen, V., Convery, J. & Cahill, S., 2006. Care revolutions in the making? A comparison of cash-for-care programmes in four European countries. *Ageing & Society*, 26(03), pp.455–474.
- Titmuss, R., 1968. *Commitment to Welfare*, London: George Allen & Unwin.
- Titmuss, R., 1970. *The Gift Relationship: From Human Blood to Social Policy*, London: Allen & Unwin.
- Tronto, J.C., 1993. *Moral Boundaries: A Political Argument for an Ethic of Care.*, New York NY: Routledge.
- Ungerson, C., 2003. Commodified care work in European Labour Markets. *European Societies*, 5(4), pp.377–396.
- Ungerson, C., 1997. Social Politics and the Commodification of Care. *Social Politics*, 4(3), pp.362–381.
- Ungerson, C. & Yeandle, S., 2007. Conceptualizing cash-for-care: the origins of contemporary debates. In C. Ungerson & S. Yeandle, eds. *Cash for Care in Developed Welfare States*. Basingstoke: Palgrave Macmillan, pp. 1–12.
- Varian, H.R., 2006. *Intermediate microeconomics: a modern approach* 7th ed., New York NY, London: W.W. Norton.
- Waerness, K., 1987. On the Rationality of Caring. In A. S. Sassoon, ed. *Women and the State: the shifting boundaries of public and private*. London: Hutchinson, pp. 207–234.
- Walker, R., 2010. *Focus on London 2010: Income and Spending at Home*, London: GLA Intelligence Unit.
- Walsh, K. & Shutes, I., 2013. Care relationships, quality of care and migrant workers caring for older people. *Ageing & Society*, 33, pp.393–420.
- Wanless, D., Forder, J., Fernández, J. L. et al., 2006. *Securing Good Care for Older People Taking a long-term view*, London: King's Fund.
- Ware, P., Matosevic, T., Forder, J. et al., 2001. Movement and change: independent sector domiciliary care providers between 1995 and 1999. *Health & Social Care in the Community*, 9(6), pp.334–340.

- Ware, T., Matosevic, T., Hardy, B., Knapp, M., Kendall, J. & Forder, J., 2003. Commissioning care services for older people in England: the view from care managers, users and carers. *Ageing & Society*, 23(4), pp.411–428.
- Wilberforce, M., Glendinning, C., Challis, D. et al., 2011. Implementing Consumer Choice in Long-term Care: The Impact of Individual Budgets on Social Care Providers in England. *Social Policy & Administration*, 45(2), pp.593–612.
- Wilberforce, M., Baxter, K. & Glendinning, C., 2012. Efficiency , choice and control in social care commissioning. *Public Money & Management*, 32(4), pp.249–256.
- Williamson, O.E., 1993. Calculativeness, Trust, and Economic Organization. *Journal of Law and Economics*, 36(1), pp.453–486.
- Williamson, O.E., 1975. *Markets and Hierarchies: Analysis and Antitrust Implications*, New York NY: Free Press.
- Williamson, O.E., 1985. *The Economic Institutions of Capitalism*, New York NY: Free Press.
- Wilson, C.B., Davies, S. & Nolan, M., 2009. Developing personal relationships in care homes: realising the contributions of staff, residents and family members. *Ageing & Society*, 29(07), pp.1041–1063.
- Yin, R.K., 2009. *Case Study Research: Design and Methods* 4th ed., Thousand Oaks, CA: Sage Publications.
- Zarb, G. & Nadash, P., 1994. *Cashing in on Independence: Comparing the Costs and Benefits of Cash and Services*, London: Policy Studies Institute.