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**PHD**

## **An Analysis Of The Treatment Of Informal Care As A Social Risk in England**

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# **An Analysis Of The Treatment Of Informal Care As A Social Risk in England**

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Submitted by

**Fiona Morgan**

A thesis submitted for the degree of Doctor of Philosophy

University of Bath

Department of Social and Policy Sciences

December 2014

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## **Abstract**

The majority of dependent older people rely on informal care to meet their long-term care needs. The activity of care-giving can place informal carers at risk of experiencing financial poverty and welfare loss, including poor health, injuries and time poverty. This thesis argues that states should recognise and treat the informal care of older people as a social risk by providing informal carers and the older people they care for with adequate statutory protection against the risks which they face.

A qualitative case study was conducted to analyse the extent to which care policies in England protect informal carers and the older people they care for against care-related risks. A policy simulation technique, the model care relationship matrix, was employed as a data collection and analysis tool. The matrices incorporated thirteen care relationship types and all of the care policy mechanisms in England, including cash benefits, care services, and employment-related support. Government documents and semi-structured interviews with practitioners and managers from a range of public sector and third sector agencies were used to determine the statutory support each care relationship would be entitled to receive. The way in which institutional structures, processes and actors within the policy environment can affect the level of statutory protection provided to care relationships was also analysed.

The study's findings reveal that the English state recognises but does not treat informal care as a social risk. The state's treatment of informal care-givers and their care-related risks is inconsistent, unpredictable and inadequate. Some informal care-givers have access to inadequate levels of statutory protection, while the risks experienced by other groups of informal carers are left unprotected and privatised. Moreover the policy environment, itself, is revealed to produce risks due to being complex, fragmented, and adversarial in nature. Overall informal carers are found to occupy a marginalised and devalued position in the English care policy system.

# Chapter 1: Introduction

## 1.1 The topic

Care is a fundamental aspect of human life. All humans share a universal need for care throughout their lives from childhood through to death, with some individuals experiencing additional needs which can require an increased level of care and support during certain periods of the lifecycle, such as old age. However, despite the universal nature and necessity of care, feminist scholars argue that the activity of caring is neither valued nor supported in capitalist society (Tronto, 1993). This thesis sets out to analyse the state's treatment of informal care in England.

The topic of informal care is one in which I have considerable personal and professional experience: as an informal care-giver for relatives with chronic, deteriorating and sometimes unpredictable health conditions; as a paid care worker in a residential care home for older people; and as a social worker working with older people and informal care-givers in local authority social services teams in England. The link between my doctoral research and my informal caring responsibilities, which have been ongoing during my doctoral studies, has afforded me a reflexive opportunity to better understand my own experiences of care-giving, and influenced the construction of my thesis. In terms of the former, the analysis of the treatment of care in capitalist society undertaken by the feminist literature has provided me with meaningful insight into my past and present caring experiences. The feminist ethic of care argument, which calls for the provision of adequate resources to enable people to have a choice as to whether to provide care or not, resonates strongly with me. I have been obliged to provide care at times on account of statutory support deficiencies and cultural norms relating to the gendered assumptions and expectations of being a daughter. Meanwhile my personal and professional experiences have supported the development of my thesis and strengthened my ability to critically engage with the literature and develop my own analytical critique of the topic. My decision to conceptualise care-giving as a risk-based activity, emanates from experiencing and witnessing the welfare and poverty risks associated with care-giving first-hand. However these personal experiences have also informed my understanding of the importance of recognising the inter-relational nature of care and acknowledging the legitimate concerns raised by disability scholars about constructing care as a burden. My decision to analyse the phenomenon of informal care using a policy analysis lens and my conceptualisation of informal care as a social risk which requires statutory protection, reveals my thesis to be constructed upon a normative assumption which does not blame those in need of care for the risks facing care-givers. Instead I

consider it to be the deficient treatment of care by the capitalist system and welfare states that create care-givers' welfare and poverty risks. My conceptualisation is therefore predicated on the view that it is the role of the state to equalise the unequal chances faced by informal care-givers and the people they care for through the implementation of social policies which provide adequate levels of support and protection (Pilj, 1994, p. 16).

The specific focus of this thesis is on analysing the state's treatment of informal care-givers who provide care to older people aged 65 and above, living in their own homes as opposed to institutional care settings. It is this group of older people who are most reliant on informal care to meet their long-term care needs. Informal care describes the care which is primarily delivered in the private domain by people well known to the care recipient, such as relatives, spouses, partners, friends or neighbours, and which is generally, although increasingly not always, unpaid (Cantor, 1991; Ungerson, 1999; Kraus et al., 2010).<sup>1</sup> The care recipients in informal caring situations are defined as individuals in need of long-term care and support due to experiencing long-term dependencies as a result of age, disability or illness (Green, 1988; Graham, 1999). The long-term care they require may cover non-health related daily living activities such as personal care as well as health care support (Kraus et al., 2010; Rummery and Fine, 2012). Informal care can also encompass a far wider remit than the provision of physical support and include the provision of '...social, psychological, emotional...attention....' (Knijn and Kremer, 1997, pp.328-30 in Sipilä et al., 2003, p. 7). This highlights the diverse nature of human care needs and the associated care activities provided by informal carers.

It is increasingly important that research is conducted which analyses the treatment of the informal care of older people by the state. Informal care remains the key source of support for older people who have health and care needs. On average between two-thirds to three-quarters of dependent older people living in OECD countries continue to rely on informal care to meet their care needs (Jenson and Jacobzone, 2000). Moreover the phenomenon of population ageing, which is linked to the growing elderly population, is leading to unprecedented numbers of people surviving into old age and experiencing chronic health problems which require long-term care support (Eurostat, 2011; Vlachantoni et al., 2011; United Nations Economic and Social Affairs, 2010). In the UK it is estimated that 1.8 million disabled adults aged 65 and over will need informal care by 2041 (National Audit Office, 2009), with the numbers of informal carers also being anticipated to increase (Pickard et al., 2007). Meanwhile due to old-age support ratios being projected to continue to decrease over the

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<sup>1</sup> In contrast paid care work is defined by Ungerson (1995) as the waged forms of care located in the public

coming decades,<sup>2</sup> care-giving is increasingly becoming ‘a widespread activity in which we are all implicated’ (Lloyd 2000, 2003, in Glendinning and Kemp, 2006, p. 268). Informal care-givers therefore constitute an extremely diverse group, as well as being a fluid category, with new people become carers every week of the year (Fry et al., 2011). The universality and diversity of the care-giving experience means that care should not be conceived as a parochial concern of women (Barnes, 2012), and as ‘women’s work’ (Graham, 1983). Neither is it acceptable for care to be treated as an invisible welfare state which is deemed to be beyond the concern of the state due to its location within the private sphere of the household (Waerness and Ringen 1987, in Jenson and Jacobzone, 2000). Feminist scholars have long since argued that states needs to acknowledge the value of care to capitalist society (Finch and Groves, 1983; Ungerson, 1987; Daly, 2002; Leira and Saraceno, 2002), and recognise care needs as a central concern of human life which affects us all (Barnes, 2012). This requires states to implement policies which award the activity of care equal citizenship rights and status as paid employment (Tronto, 1993; Williams, 2004; Barnes, 2012; Rummery and Fine, 2012); and ensure that the risks and costs associated with care are socialised rather than being privatised to the affected individuals.

Over the past few decades states have begun to implement policies to support older people with long-term care needs and informal carers in their caring role. It is necessary to undertake a thorough analysis of these policies so that the state’s treatment of informal care and the care-related risks associated with this activity can be comprehensively assessed. For existing research highlights how the need for care and the provision of care can produce extensive types and levels of risks for informal carers and the older people they care for. Informal carers can experience financial poverty, time poverty, and welfare risks due to the activity of caring: acting as a barrier to labour market participation; causing injuries; contributing to health problems; and causing the carer’s own needs to become subsumed by those of the person they care for (Tronto, 1993; Bittman, Fast, et al., 2004; Jenson, 2004; Lundsgaard, 2005; EUROFAMCARE Consortium, 2006). Care-related risks can also be inter-related. If a care-giver experiences any of these aforementioned risks it can undermine their ability to provide good quality care, thereby placing the care-receiver at risk of experiencing welfare loss.

The feminist literature has primarily examined the treatment of care by the state from a citizenship and social rights perspective, with a primary focus on child care. This thesis applies a different analytical lens and focuses on analysing whether states recognise and treat the informal care of

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<sup>2</sup> From 3.7 adults (aged 20 to 64) per older person in 2008, to 2.4 adults by 2050 (OECD, 2011).



older people as a social risk which requires statutory protection.<sup>3</sup> For informal care to be recognised and treated as a social risk, states must assume responsibility for providing comprehensive social protection to all those requiring and providing care through the implementation of care policies which provide adequate time, money and support. Baldwin (1990) notes how states vary considerably in the level of risk protection they provide to risk-prone groups and consequently the extent to which risks remain either privatised or socialised. Each national care policy environment therefore requires careful analytical scrutiny in order to assess the extent to which states recognise and protect the diverse range of risk-bearers against the care-related risks which they face. This thesis uses England as an empirical case to conduct an in-depth study of the extent to which informal care is treated as a social risk by the English state.

## 1.2 Research objectives

This research aims to investigate the extent to which the English state treats informal care as a social risk by asking the following research questions:

- How do welfare state care policies treat the care-related risks of different types of informal care-givers and the older people they care for in England?
- How far and in what ways do these policies recognise and treat informal care as a social risk which requires public support and protection?

This thesis contends that for informal care to be treated as a social risk it would require state policies to provide adequate and consistent protection to **all** groups of risk-bearers against the care-related risks they face.

In order to answer these research questions and achieve this research objective it requires a comprehensive analysis of the entire English care policy environment to be undertaken; and the treatment of different types of risk-bearers across the complete range of care policies to be analysed. This in-depth analysis of the whole care policy system requires the following dimensions to be covered.

- Firstly, the complete array of policy mechanisms available across different policy domains which protect care-givers and care-receivers against care-related risks. This includes: cash benefits which can alleviate current and future poverty risks; care services which can alleviate welfare risks by providing carers with support and a break from their caring role

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<sup>3</sup> I consider that social rights to statutory support and protection often emerge out of states recognising a particular contingency as a social risk which leads them to offer statutory protection to affected individuals and groups of risk-bearers.

through the provision of replacement care services; and employment support either from Jobcentre Plus to enter the labour market or through the provision of care leaves and flexible working which can support carers to reconcile their work and caring roles and reduce time poverty risks.

- Secondly, the eligibility criteria and the policy output<sup>4</sup> associated with each policy mechanism need to be analysed. This is because variations in the recognition and treatment of different types of risk-bearers can be discerned by analysing the characteristics and principles of entitlement which the state uses to determine eligibility across policy mechanisms. Moreover, the level of statutory protection provided to different groups of risk-bearers against the care-related risks they experience also enables the adequacy and consistency of the support provided to be assessed.
- Thirdly, the way in which policy mechanisms are implemented in practice also needs to be analysed. This is because the institutional processes and negotiations through which individuals gain access to statutory support, and the discretionary decision-making of statutory agencies and practitioners, can significantly affect the policy entitlements awarded to risk-bearers.

It is only through incorporating each of these care policy elements (outputs, governance arrangements, institutional processes and actors) into the analysis, that it is possible to assess the extent to which the multi-dimensional risks faced by different types of informal care-givers are recognised and protected by states, and a definitive conclusion about the state's treatment of informal care can be reached.

### **1.3 Research methodology**

To achieve these research objectives a qualitative research strategy was devised utilising a case study design which encompassed the English care policy environment. The key research tool used to collect the research data was the model care relationship matrix, a type of policy simulation tool influenced by the model family approach. The matrix design consisted of two key elements and incorporated a number of innovations. Firstly, it contains all of the care-related policy mechanisms available in England across the cash benefits, care services and employment support<sup>5</sup> domains. Secondly, it contains 13 vignettes, each of which represents a particular care relationship scenario

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<sup>4</sup> I utilise Mitchell's (1991) definition which considers policy outputs to mean the actual size and incidence of the statutory transfer, which in relation to my research includes the cash transfer, level and type of service provision, or the statutory right to a particular type of support. This research does not consider the policy outcomes of these state interventions for informal carers and the people they care for.

<sup>5</sup> For carers in work and seeking work.

featuring an informal carer and an older care-receiver. To ensure that the vignettes reflected the diversity of care relationships in England, their selected characteristics were based on empirical data about informal care-givers and older care-receivers in England. It is important to note at this point that using this dyadic unit of analysis which incorporated older care-receivers' entitlements as well as informal care-givers' entitlements within the data collection and analysis process, was intended to facilitate a holistic analysis of the state's treatment of informal care as a social risk. In order to analyse the extent to which informal carers' care-related risks are protected by the state, it requires consideration of the extent to which state policies, processes and practitioners recognise and manage the inter-relational nature of care and care-related risks. This involves examining the type of statutory protection that is available for older care-receivers and analysing the extent to which the statutory protection provided to informal carers can be both necessarily, and at times unnecessarily contingent upon the statutory support provided to the care-receiver.

The data collection phase of the research took place during the latter half of 2012, with the cash benefits rates being relevant for the duration of the financial year April 2012 to March 2013. The model care relationship matrix provided a systematic framework for recording the type and level of statutory support each care relationship type would be assessed to be entitled to receive across all the policy mechanisms in the care policy system. A range of data sources were used to complete the matrix. These included secondary data from government sources including legislation, policy regulations, websites, and application forms. Primary data were also gathered by undertaking semi-structured interviews, and the occasional questionnaire, with a range of front line practitioners and managers from statutory and third sector agencies across the different policy domains. Two localities were selected in which to conduct the care services and Jobcentre Plus (JCP) interviews because both types of support are decentralised to local authorities and locality JCP offices and districts to implement respectively. Moreover, several practitioners were interviewed in each local authority to take account of practitioner discretion affecting policy outputs. Meanwhile the cash benefits and in work employment support data were obtained from national level data sources because these areas of statutory support are determined by central government. Interviews were also conducted with national government and third sector policy-makers in order to obtain their views about the treatment of informal care by state policies overall and the role of the national carer strategies.

The research data that were obtained facilitated a micro-level and macro-level analysis of the treatment of informal care by the English state. The matrix data exposed the logics of the care

policy system and revealed the variations and inconsistencies in the assessed policy outputs of different types of care relationships across policy domains, policy mechanisms, localities, and practitioners. This helped to reveal how state policies, agencies and practitioners may only recognise and socialise the care-related risks experienced by particular groups of risk-bearers, while other groups' risks go unrecognised and unprotected, leaving their risks privatised. Meanwhile, the research data were also analysed from a macro level perspective in relation to what the institutional structures, processes and actors located within the care policy environment could reveal about the state's treatment of informal care overall.

## **1.4 Applications of the research**

The outcomes of this thesis will contribute to the existing academic literature in a number of ways.

- It will contribute to the social risk literature by undertaking a more thorough conceptualisation of social risk than has previously been undertaken within the social risk literature; making a case for informal care being considered a social risk which requires the protection of the state; and undertaking an empirical case study to analyse the extent to which the English state treats informal care as a social risk.
- It will contribute to the care policy literature by undertaking an in-depth, comprehensive, empirical analysis of the English care policy environment which provides a thorough assessment of the overarching treatment of informal care by the state across policy domains, localities, and practitioners. This analysis will also provide a solid foundation for reflecting upon the effectiveness of the national carer strategies and the recent legislative reforms affecting support for informal carers in the care services and employment domains.
- It will contribute to the feminist literature by analysing the care policy environment from the perspective of a diverse range of informal care-givers and assessing their treatment on account of their age, the level of care provided, their financial circumstances, employment and relational status etc. Undertaking this holistic analysis of the English care policy terrain will also facilitate consideration of whether an ethics of care is present and practised in the English case.
- It will contribute to the research methodology literature due to the innovations undertaken in the design of the policy simulation tool, which enables the treatment of the caring dyad to be analysed across multiple policy domains within one national context.

The research findings will also make an empirical contribution by revealing the weaknesses found within the current care policy system and making policy recommendations to improve the statutory protection that is offered to care relationships and informal care-givers.

- It will highlight the inconsistencies and gaps in the statutory support and protection that is provided to informal care-givers across the care policy environment that need to be eradicated and filled respectively.
- It will expose how the existing policy system can produce risks and how these need to be addressed in order to make the system more user-friendly and reduce the potential for conflict between members of the caring dyad and other actors.
- It will show how institutional processes can undermine the wellbeing and choice of those providing and receiving care, and identify what needs to be done to ensure that the policy environment is reconstructed according to an ethics of care.

## **1.5 Chapter outline**

Chapter 2 undertakes a review of the feminist and disability literature and provides an overview of the conceptualisation of care. It begins by discussing the parameters of care in terms of it being an activity, and also a relationship which requires the inter-relational nature of care and the power differentials that can exist within care relationships to be recognised. The feminist conceptualisation of care as a burden is also explored and critiqued, and informs my subsequent conceptualisation of informal care as a risk-based activity. The chapter moves on to examine the gendered dimension of care, including the feminist analysis of how care has been constructed as a female domain which contributes to its devalued position within capitalist society and its treatment by welfare states. The feminist literature is critiqued in order to highlight how men are increasingly providing informal care and that the lack of value attributed to care by states due to its gendered construction affects all care-givers and care-receivers, no matter what their gender. The chapter concludes by considering how the feminist ethics of care needs to be applied to the treatment of care by states in order that care can be truly valued by society and those engaged in care can be provided with adequate protection and choice through state policies.

Chapter 3 provides the theoretical framework for the thesis and reviews the social risk literature. It begins by considering how the literature makes the distinction between the old social risks which were recognised by states during the industrial era and the new social risks which have been emerging during the post-industrial era. Through undertaking this review it becomes apparent that the informal care of older people is not properly acknowledged as a social risk in the literature, and

the remainder of the chapter serves to address this gap. Firstly, the case is made that the social risk literature does not adequately conceptualise social risk. This is addressed by identifying the specific characteristics which make a contingency a social risk, and the factors which lead to states recognising a contingency as a social risk. This conceptualisation is then applied to making an evidence based case that informal care is a risk-based activity and features the required characteristics for it being recognised and treated as a social risk by states. The chapter moves on to explore how factors including demographic and labour market changes, and claims-making by affected groups of risk-bearers, are contributing to states increasingly implementing care policies, and that this would appear to indicate that they recognise informal care as social risk. This sets the scene for justifying the need to undertake an empirical analysis of the English case in order to assess the extent to which state care policies actually treat informal care as a social risk and recognise all risk bearers to require statutory protection.

Chapter 4 provides the empirical framework for the study by undertaking a review of the existing care policy literature and exploring what is already known about the English care policy context. It begins by reviewing the comparative care regime literature in order to identify the English care regime type and undertake a scoping exercise of the key policy mechanisms which are used by states to support older people and informal carers, including cash transfers, care services, and employment policies. The chapter then moves on to review those studies which explore the English care policy context and examines the existing literature about the English state's treatment of informal care. These studies tend to focus on the care services domain, and explore individual aspects of the governance arrangements, institutional and inter-personal factors, such as localism, eligibility criteria, practitioner discretion, and personalisation, and how these can affect individuals' statutory entitlements. This chapter concludes by stating that a more comprehensive and nuanced analysis of the treatment of informal care by care policies in England is required.

Chapter 5 describes and justifies the research methodology used for this study. It sets out the interpretivist nature of my qualitative study. It justifies the selection of a case study design containing comparative elements. It describes the research methods that were used, and features a detailed account supported by empirical data of how the model care relationship matrices were constructed. The data collection methods are described along with the decision-making around how the localities and research participants were selected. The challenges encountered in conducting the fieldwork are also discussed. The ethical issues raised by the research together with the strength

and limitations of my methodological choices are reflected upon. The data analysis process, including how the data were organised and subsequently analysed, is also explained.

Chapters 6 to 8 set out the empirical findings of the research. The findings in Chapter 6 are based on the analysis of the care relationship matrix data. The chapter sets out the different types of characteristics that states use to determine eligibility and attempts to determine which are the most significant for care relationships accessing support and protection in the English care policy environment. It reveals how conditions and principles of entitlement, practitioner decision-making, localism and personalisation can significantly affect the consistency of the statutory support and protection available for different types of informal care-givers and care relationships. Characteristics are shown to be treated inconsistently and in contradictory ways across policy domains, policy mechanisms, the members of the caring dyad, types of carers, and localities. These variations contribute to some risk-bearers receiving statutory protection against care-related risks while others are only partially protected or are left unprotected by the state.

Chapter 7 undertakes a macro level analysis of the institutional structures and processes contained within the care policy environment, and considers how these constructions produce the unequal policy effects revealed in Chapter 6. This analysis considers the implications of the complexity and fragmentation of the overarching policy system for care relationships. The institutional processes contained within each policy domain are also analysed which allows key trends in the treatment of informal carers by the state across all three policy domains to be identified. This reveals institutional absences in statutory protection for particular types of care relationships; the weakness of carers' rights; and shows how policies are often designed to meet the needs of other groups of risk-bearers. This chapter helps to expose the wider structural positioning of carers within the policy system, which permits the overarching treatment of informal care and care-givers by the state to be assessed.

Chapter 8 analyses the role of actors and negotiation processes operating within the care policy system and how they can affect care relationships accessing the statutory support that is actually available. Inter-personal as well as institutional factors are revealed to affect the extent to which the caring dyad's risks are either protected, maintained or exacerbated. Moreover the complex and adversarial nature of the policy system itself is also noted to produce risks which can impede access to statutory protection and have negative implications for the social relations of those engaged in the policy system.

Chapter 9 forms the discussion chapter in which the findings are linked back to the existing literature; the research questions are answered about the extent to which the English state recognises and treats informal care as a social risk; and policy recommendations are made about how the state can improve the support and protection that is provided to informal carers. This chapter also reflects upon the policy-making process and the factors which have influenced the development of care policies in England, taking into account the claims-making of carers' organisations, and the potential implications that key policy reforms in 2014 will have for the statutory entitlements of informal carers. This chapter concludes by analysing the overarching findings of this research project about the treatment of informal care by the English state from the perspective of an ethics of care. A final conclusion chapter presents reflections about the contribution of this study to the wider literature, the strengths and limitations of the research project and suggests opportunities for future research.



## Chapter 2: Conceptualising Care

### 2.1 Introduction

Care is a simple word which reflects a complex empirical reality. In this chapter the concept of care is explored and the key dimensions of care which have been conceptualised in the literature are reviewed. This will support the intention to analyse the extent to which welfare states, and the English state specifically, recognises and supports the different dimensions of care through the care policies they implement. The feminist literature is the primary focus of this literature review because it is the main area of scholarship which considers care to be a social phenomenon worthy of academic consideration. However, this chapter also considers the contribution of the disability literature which has criticised the feminist construction of care as an oppressive formulation, thereby highlighting its contested nature.

In the first part of this chapter the parameters of care are examined. The activity of care is explored in order to ascertain what counts as care and identify which elements of care, as a physical and emotional activity, are contested. The temporal dimension of care is examined in order to highlight that the informal care of older people contains unique risks associated with the unpredictability of care in old age which can have significant implications for care-givers. The way in which caring is conceptualised as a burden for women by the feminist literature on account of the labour and opportunity costs it entails is also explored. The disability literature's criticism of this conceptualisation and its exposure of the relational dimension of care which involves complex power dynamics that can serve to oppress the care-receiver as well as the care-giver are considered. All these elements support my conceptualisation of care as a risk-based, relational activity which is subsequently applied to my analysis of care as a social risk in Chapter 3.

The second part of this chapter focuses on how the feminist literature is also crucial for providing explanations for the treatment of care and care-givers in capitalist societies. The macro level analysis of care by feminist scholars has exposed the gendered construction of caring work. However, much of this analysis has focused on child care and how caring work has 'reinforced the disadvantaged position of women' in society (Daly and Lewis, 1998, p. 4). The recognition of the significant contribution that men make as informal carers who are equally disadvantaged by the gendered construction of care and its devalued position within society, has been less forthcoming. The ethic of care argument developed by feminist scholars which addresses some of these

shortcomings is also explored. The literature argues for the right to receive care and the right to provide care to be classed as citizenship rights and for care to be awarded statutory protection of equal value to that which is attributed to work. This conceptualisation of the ethic of care will ultimately provide a useful framework with which to analyse my own findings in relation to the overarching treatment of informal care by the English state.

## **2.2 Defining informal care**

It is necessary to first clearly set out and define the type of care my thesis is focused on. This thesis seeks to analyse the treatment of informal care-givers by state care policies who provide informal care to older people aged 65 and over. The literature defines informal care as the care which is undertaken in the context of unpaid domestic labour in the private domain of the household as part of either kinship and marital relations, friendship or neighbourliness (Graham, 1999; Williams, 2004; OECD, 2005; Barnes, 2012). Consequently informal care relationships exist between people by virtue of their pre-established social relationship. The literature has explored the diverse motivations underpinning the decision to provide informal care to elderly relatives. Informal carers may be influenced by feelings of love, compassion and gratitude but also social obligations, normative rules and other incentives relating to responsibility,<sup>6</sup> reciprocity and financial incentives (Qureshi and Walker, 1989; Finch and Mason, 1991, 1990; Ungerson, 1987, 1995; Daly, 2001; Mooney et al., 2002). Even so, no matter whether informal care is initially provided out of love or duty, Ungerson (1987) found neither motivation to be a static nor steady state, for both could alter during the course of a care relationship.

There is a need to define the distinction between informal care and formal care because the boundary is becoming increasingly blurred. Formal care is defined as care which is generally undertaken by professional care workers located in the public sphere of paid employment who are paid a formal wage on either a bureaucratic or contractual basis by the care-receiver or a proxy (i.e. the state) to provide a care service to the care-receiver (Ungerson, 1987, 1995; Qureshi and Walker, 1989; Leira and Saraceno, 2002). Consequently these care relationships are generally set up between strangers under specific service conditions for specific ends (Thomas, 1993, p. 652). However, informal care is increasingly being affected by commodification and formalisation processes through the implementation of statutory cash payments. These payments are either paid

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<sup>6</sup> Kinship hierarchies in western industrialised societies were revealed by Qureshi and Walker (1989) to be powerful for determining who undertakes care-giving responsibilities for older relatives. The hierarchy ranging from the highest to lowest obligation was; spouse -> relative living in household -> daughter -> daughter-in-law -> son -> other relative -> non relative.

by the state directly to the informal care-giver or are provided to the care-receiver which they can then use to employ their informal care-giver (Ungerson, 1995, 1997). Either way these policy mechanisms ensure that ‘...the cash nexus enters the care relationship in the domestic domain’ (Ungerson, 2004, p. 190), with the most formalised of these statutory arrangements introducing a formal employment contract into the relationship between informal care-givers and care-receivers (Knijn and Ostner, 2002, pp. 158–159). Even so, this type of paid care can still retain the identity of informal care as long as the care relationship is underpinned by pre-existing emotional ties or kinship obligations (Lundsgaard, 2005, p. 10).

It is important to note that the pre-existing nature of informal care relationships can contribute to the informal care that is provided not being recognised by the people engaged within them (Barnes, 2012). Individuals may not identify themselves as ‘carers’ nor what they do as ‘caring’ for a variety of reasons. Some individuals may view the care they provide as a natural part of their relationship with the other person, in their relational roles as husbands, wives, children, siblings etc. (Ungerson, 1987; Henderson and Forbat, 2002; Yeandle et al., 2007; Molyneaux et al., 2011). Consequently, spouses may not recognise themselves as carers due to perceiving care to be an implicit bargain within the reciprocal marriage contract (Dalley, 1996, p. 17). Meanwhile, co-residential caring may go unnoticed because the additional tasks are absorbed into the normal running of the household and are therefore not easy to distinguish (Bittman, Fast, et al., 2004, p. 85). O’Connor (2007, p. 170) also noted how the ‘care-giver’ identity is very rarely ‘sought, embraced or consciously taken on’ and may only be reluctantly acquired by an individual as a passport to access public services and support. These labels may also be actively resisted due to both members of the caring dyad being reluctant to change or strain their relationship by publically acknowledging their disparate needs and resulting tensions caused by needing or providing care (Oliver, 1983; Bittman, Fast, et al., 2004; O’Connor, 2007).

### **2.3 The dimensions of care**

The key dimensions of care discussed within the literature will now go on to be examined. This will involve setting out the parameters of care, as a need, an activity, a burden, a relationship, as well as its temporal dimensions, so that the concept and implications of care can be fully understood. This review in turn will support the development of my own analytical framework. It will support me to make the case that informal care is a social risk and will enable me to clearly disaggregate, identify and analyse, the elements of informal care which states recognise within their care policies. This review will also highlight some of the gaps and contested elements of the feminist literature’s

conceptualisation of care caused by its focus on child care, and informal care-givers rather than care-receivers.

### 2.3.1 The activity of care

This section explores the range of activities which have been recognised as caring activities in the literature. Care is a basic, universal human need which is integral to the human experience throughout the life course (Daly and Standing, 2001, p. 2). Even so, it is evident that humans require more specific and intensive forms of care during periods of higher dependency, such as childhood, and when experiencing illness and disability at any age. The literature describes a range of activities to constitute care. However, while some components of care are universally applicable across different age groups, other components and specific care activities are only categorised as being relevant at specific stages of the life-course or according to a person’s specific health condition. To illustrate this point Figure 1 provides a synthesis of examples taken from the existing literature, which are supplemented by my own italicised additions. Together these highlight the similarities and differences between the types of care needs and care activities required by dependent older people and children.

**Figure 1: Categorising care activities**

<b>Care Activities for Dependent Older People<sup>1</sup></b>	<b>Care Activities for Children</b>
<p><b>Help with personal care<sup>2</sup></b>            Bathing, washing, dressing, feeding, continence management, <i>overall hygiene (including oral hygiene and nail care)</i></p>	<p><b>High contact childcare</b>            Face to face interaction revolving around physical care including feeding, bathing, diapering, dressing, holding</p>
<p><b>Help with general health care</b>  <i>Support with arranging and attending medical/health care appointments, giving medicine</i></p>	
<p><b>Help with specialised health care</b>            Administering injections, changing dressings, <i>managing medical equipment (colostomy bags, catheters, breathing equipment, feeding tubes)</i></p>	
<p><b>Help with physical functioning/mobility/travel</b>            Physical help with lifting, getting in and out of bed, up and down stairs, <i>walking inside and outside of the house, support with using or providing transport</i></p>	<p><b>High contact childcare</b>            Putting to bed, carrying  <b>Travel (including waiting time)</b>            Transportation to school and activities</p>
<p><b>Help with domestic and household tasks<sup>3</sup></b>            Shopping, preparing meals, housework, household and garden repairs and maintenance</p>	
<p><b>Administrative and financial tasks</b>            Help with correspondence, administration and financial matters including bills and money management</p>	

Care Activities for Dependent Older People <sup>1</sup>	Care Activities for Children
<b>Social Support and Interaction</b> Keeping person company and taking them out <i>to participate in wider family and community activities and networks</i> including religious activities	
<p style="text-align: center;"><b>Communication</b></p> <p>Supporting the communication of someone who cannot understand or be easily understood</p> <p style="text-align: center;"><b>Care Management</b></p> <p>Representing <i>and communicating about the person either by writing, telephone or in person, with other family members, professionals or services. Co-ordinating care provision.</i><sup>4</sup></p>	<p style="text-align: center;"><b>Communication</b></p> <p>Communication with the child (see developmental needs)</p> <p>Communication about the child either in person, by writing or telephone with other family members, teachers and other professionals and service providers.</p>
<p style="text-align: center;"><b>Monitoring safety</b></p> <p>Anticipating, protecting and keeping an eye on the person to make sure they are safe during the day and at night.</p>	<p style="text-align: center;"><b>Low intensity child care</b></p> <p>Supervisory responsibilities; supervising activities and play, maintaining a safe environment, keeping an eye on sleeping children</p>
	<p style="text-align: center;"><b>Developmental Needs</b><sup>5</sup></p> <p>Support development of cognitive, linguistic and social skills through teaching, play, communication and interaction</p>
<p style="text-align: center;"><b>Emotional Support</b></p> <p>Comforting</p> <p style="text-align: center;"><b>Emotional labour</b></p> <p>Thinking about, being alert to and recognising the needs and wants of others</p>	<p style="text-align: center;"><b>High contact childcare</b></p> <p>Cuddling, hugging, soothing</p>

Sources: (Parker, 1981; Qureshi and Walker, 1989; Parker, 1992, p. 10; Bittman, Craig, et al., 2004; Budig and Folbre, 2004; Bittman, Fast, et al., 2004; Wolf, 2004; Arber and Venn, 2011).

*Note:*

<sup>1</sup> This list is applicable to individuals of any age with some degree of physical or mental incapacity.

<sup>2</sup> Personal care tasks also known as Activities of Daily Living (Lundsgaard, 2005).

<sup>3</sup> Practical tasks also known as Instrumental Activities of Daily Living (Lundsgaard, 2005)

<sup>4</sup> Also referred to as 'managerial or organizational labour' (James, 1992; Arber and Venn, 2011).

<sup>5</sup> It could be argued that dependent adults also have educational needs in order to keep them mentally stimulated however this is not acknowledged in the literature.

This categorisation exercise helps to expose the multi-faceted nature of the activity of care within and across life-course stages. Even then this list is by no means exhaustive. Standing (2001, p. 19) notes that care work is infinitely variable, which is why caring is always experienced as an unspecific and unspecifiable kind of labour, the contours of which shift constantly (Graham, 1983, p. 26). Moreover, the categorisation of all these tasks as caring activities is not without contention, which helps to expose the fluid and ambiguous nature of care. This ambiguity is important to realise for it can affect the types of care activities which states may offer to provide care-receivers or care-givers assistance with.

The literature makes the distinction between care activities and domestic servicing work. The latter being defined as those domestic tasks required to run a household which all household members benefit from. However, the life-stage of the care recipient and location of the care provision can affect how domestic tasks are categorised. For example, Dalley (1996, p. 39) used the term 'servicing' to describe the maintenance functions performed by wives to service those already engaged in productive labour (husbands) and to support the reproduction of those who will engage in productive labour in the future (children). According to this definition, dependent adults who are no longer engaged in productive labour are recipients of care rather than servicing when in receipt of domestic management and maintenance tasks (Qureshi and Walker, 1989, p. 74). Moreover, Bittman et al. (2004, p. 80) found that where household chores are undertaken for a dependent adult living in a separate household they are counted as care because they occur outside the care-giver's home which prevents the care-giver from undertaking the task as a form of joint production. In contrast a parent making a child's meals is counted as servicing within time-use surveys (Budig and Folbre, 2004, p. 52; Bittman, Fast, et al., 2004), because the care-giver is undertaking a domestic task which meets their own needs at the same time as fulfilling the needs of the care recipient (Wolf, 2004). However, within multi-generational households care-givers may have to undertake separate household tasks for the elderly care-receiver if they are subject to different requirements from the rest of the family. Consequently the meal preparation for the children and husband would count as servicing, whilst the meal for an older person with different dietary requirements would count as care (Walker, 1983; Qureshi and Walker, 1989).<sup>7</sup>

Further distinctions are made between health care and long-term care needs and activities, not least by health and social care professionals who clearly distinguish between which element of care they will provide support with (Twiggs and Atkin, 1994). Curative and rehabilitative health care is defined as that which aims to change the medical condition of the person, while long-term care compensates for a lasting inability (Lundsgaard, 2005, p. 9). According to this categorisation, support with medical care does not constitute a long-term care or social care activity. Even so, informal care-givers who are not required to adhere to professional boundaries are often required and relied upon to provide support and interventions in relation to the care-receiver's health and medical needs (Larkin and Milne, 2014). Similarly, providing support with social interaction (Lundsgaard, 2005) and co-ordinating care management arrangements and appointments are not always recognised as constituting a long-term care activity (James, 1992; Rosenthal et al., 2007;

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<sup>7</sup> Similarly the laundry of someone who experiences incontinence would be undertaken as a separate care task.

Arber and Venn, 2011). However, once again both activities may form an important element of the support an informal care-giver provides to an older person (Watson and Mears, 1999).

In the case of care as an emotional activity the literature has distinguished between different emotional components. The literature initially made the distinction between 'caring for' someone as demonstrated in the physical activity of one individual 'tending' and servicing another person's needs, and 'caring about' someone whereby care constitutes the emotional activity of feeling love, respect, concern, consideration and affection for the wellbeing of others (Parker, 1981; Graham, 1983; Ungerson, 1983a). The latter can physically manifest itself in the provision of emotional support to the care-receiver, including being available, listening to, taking time with the person, and being attentive (Watson and Mears, 1999). However care as an emotional activity can also concern the privately experienced feelings of the care-giver and their publically expressed emotional input in the care relationship (Thomas, 1993, p. 663), as well as the emotional response of the care-receiver to the provision of care. This can involve negative emotions on the part of both members, such as resentment, anger, embarrassment and indifference, as well as positive emotions. Either way these emotions can significantly affect the way in which care is given and received because the type of emotion experienced and expressed becomes part of the care process (Barnes, 2012, p. 170). The extent to which the practical and affective elements of care can be treated as separate entities has been debated in relation to the provision of both informal and formal care (Waerness, 1984; Qureshi and Walker, 1989; Ungerson, 1990; Qureshi, 1990; Standing, 2001). However, it may be argued that care support which is provided in situations where there is a deficit of emotional support, a lack of sensitivity and respect for the emotional and bodily dimensions of people's experiences, or a surfeit of negative emotions, cannot be considered to constitute care at all (Barnes, 2012; Rummery and Fine, 2012).

### **2.3.2 The temporal dimension of care**

Understanding the temporal dimension of care is of fundamental importance for understanding how the need for care and the activity of care can impact on people's lives. Moreover, the care of older people contains unique temporal elements which need to be taken into account by policy-makers if policies are to respond effectively to the needs of care-givers and care-receivers. Unlike child care,<sup>8</sup> the care needs and care provision of dependent older people is characterised by unpredictability.

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<sup>8</sup> Dependency in childhood is a universal and predictable experience because the care requirements of healthy children at each developmental stage can be determined by their age (Budig and Folbre, 2004; Ironmonger, 2004). Consequently parents are more aware and able to calculate the approximate time commitment that will be required to provide the necessary care to their children.

This is because dependency in old age is unpredictable and selective, affecting many but not necessarily all individuals. This unpredictability can affect a range of time-related dimensions of care needs and care provision including; onset, duration, intensity, complexity and prognosis (Parker, 1981; Pilj, 1994; Mooney et al., 2002). Consequently, care-givers can face an uncertain time commitment in relation to both the immediate daily care provision they need to provide and also the long-term duration of future care provision. This unpredictability can have significant implications for the care-giver's own life and the care-related pressures they experience.

The onset and duration of the care support that is needed in old age is difficult to predict. It is unlike the care support required by children whereby the birth of a child is a predictable event and the duration of a healthy child's physical dependence on parental care is measurable, steadily tapering off due to it being 'a relatively short-term and diminishing condition' (Moss, 1982, p. 122; Wolf, 2004). The care of older people sees this process taking place in reverse (Walker, 1983, p. 110). The onset of the need for care in old age is unknown. It can begin suddenly with an acute health episode such as a stroke, or gradually due to the cumulative progression of chronic illnesses such as arthritis or Alzheimer's Disease (Mooney et al., 2002). The duration of older people's care dependency is also uncertain. Health conditions are subject to variable trajectories across individual cases (Glendinning, 2008), moreover the need for care may be permanent, temporary, or intermittent. Ultimately the ageing process leaves older people requiring increasing levels of care support as their health and functional ability deteriorates, resulting in an irreversible state of dependency which will only end in death (Wolf, 2004, p. 110). Even so, although the ultimate prognosis remains the same for everyone, it is impossible to predict the duration of the care provision required and at what point in any scenario the need for care in old age will end.

The intensity and frequency of care provision can also vary on account of the type of care task an individual requires help with and their health condition. As Twigg (2008, p. 233) notes the body has its own temporality, which is rhythmic and cyclical and guided by organic processes. So while the need for support with accessing the toilet will require more frequent care provision than help with shopping, it remains a more unpredictable need in terms of the length of time required to perform the task and the frequency with which the task needs to be undertaken. The level of dependency of the care-receiver which is affected by their specific disability or health condition can also affect the intensity of care provision (Qureshi and Walker, 1989). Those individuals with more complex physical or mental health needs and higher levels of functional dependency will require more frequent support. Moreover, the physical and mental responsiveness of the care-receiver can affect



the amount of time required to undertake specific tasks. People with long-term illnesses or disabilities are also likely to experience changes in their symptoms over time (Glendinning, 2008). This can cause their functional ability to fluctuate leading them to require different levels of support with different tasks at different times. These fluctuations can occur during the course of the overall care journey but can also affect the level of care required on a day to day basis, with people having 'good days', 'bad days' and the odd or increasingly frequent crisis thrown in.

Twigg (2008) describes the tempo of care-giving to be unpredictable, switching between more passive forms of care, routine and repetitive low level care tasks, and urgent interventions to prevent or deal with crises. In terms of the former, care has to be provided when it is needed, and generally needs to be provided close to the care-receiver either in relation to their body or home (Twigg, 2008). The unpredictability of many care needs and care-related incidents, such as falls, and the need for responsive and proximate support can require care-givers to provide passive forms of care which can have significant time-related implications. This type of care does not require active involvement from care-givers but requires them to be on 'standby' or 'on call' in a state of readiness to perform an activity if needed (Standing, 2001; Budig and Folbre, 2004, p. 59; Bittman, Fast, et al., 2004). This may require the care-giver to be in the same room or household as the potential care-receiver, keeping a watchful and alert presence even when the care recipient is asleep so as to provide immediate assistance when necessary (Budig and Folbre, 2004). This type of care can be as time-consuming as the provision of physical support (Smeeding and Marchand, 2004). Although Ungerson (1983a) notes that time devoted to supervisory care can be utilised simultaneously for carrying out other non-caring tasks, other studies found that even just keeping an eye on elderly relatives ensured that non care-related household tasks took care-givers more time to complete (Qureshi and Walker, 1989, p. 17). Undertaking physical caring tasks, and I would include certain types of supervisory care,<sup>9</sup> meanwhile, is a highly demanding form of focused interaction (Bittman, Craig, et al., 2004). Caring time can therefore be fractured and fragmented (Watson and Mears, 1999), with different care activities requiring different levels of personal engagement on the part of the care-giver (Budig and Folbre, 2004). However, all forms of care are time-consuming which can have significant implications for the care-giver fulfilling their own self-care needs and the needs pertaining to their wider networks (Twigg, 2008). The implications of the temporal unpredictability of old age dependency for informal care-givers and the time constraints associated with care-giving will be explored in the next section.

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<sup>9</sup> For example, providing verbal prompts to support an individual with dementia to undertake and sequence a care task themselves.

### 2.3.3 Care-giving as a burden

Care has been conceptualised as a burden in the feminist literature. This conceptualisation has emerged in part out of micro level empirical studies which have been used to illustrate the opportunity costs experienced by care-givers. These emphasised the ‘physical and mental burdens’ (Qureshi and Walker, 1989, p. 92) and ‘daily grind’ (Bayley, 1973, p. 208)<sup>10</sup> associated with care-giving from the perspective of female care-givers whose lives had been disrupted by caring (Twiggs and Atkin, 1994, pp. 3–4). This conceptualisation has also been influenced by macro level feminist sociological theorising and analysis. This sought to draw attention to women’s exploitation through their unpaid domestic work (Knijn and Ostner, 2002, pp. 154–155) and to explain how the construction of the domestic sphere as a female domain has restricted women’s choices, economic independence and employment opportunities within the public domain. This evidence and analysis has helped to identify the risks which are inherent within the provision of informal care. However, this feminist conceptualisation has been severely criticised by the disability literature for oppressing and neglecting care-receivers.

Empirical research undertaken by feminist researchers has focused on how informal care-giving can have short-term and long-term negative effects on multiple domains of care-givers’ lives, including physical, emotional, psychological and economic impacts (Finch and Groves, 1980; Parker, 1990; Watson and Mears, 1999; Wolf, 2004). Care-givers are revealed to face economic costs on account of the time-consuming nature of care-giving and the unpredictability of the care-receiver’s care needs. This can make it difficult for care-givers to combine caring with paid employment resulting in them reducing their working hours or giving up work altogether (Wright, 1983; Ungerson, 1987; Bittman, Fast, et al., 2004; Schmid et al., 2012). This in turn can undermine their economic and financial security (Graham, 1983, p. 25) by causing: lower lifetime earnings and future pension entitlements; slower career advancement (Wright, 1983; Walker, 1983; Rimmer, 1983; Smeeding and Marchand, 2004; Bittman, 2004); and making them potentially reliant on private or statutory cash transfers as a primary source of income.<sup>11</sup> Care-giving can also undermine care-givers’ wellbeing due to the labour involved having negative effects on their health, relationships and leisure time (Parker, 1990; Jenson and Jacobzone, 2000). For the amount of time spent providing care can obstruct care-givers from managing their own time and needs or may make them too exhausted to use their remaining time as they might otherwise choose to (Ungerson, 1983a; Watson

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<sup>10</sup> Described as ‘a wearing, routine servicing of basic functions with no prospect of any diminution of the work involved’ (Baldwin and Glendinning, 1983, p. 55).

<sup>11</sup> Moreover, the recovery or death of the care-receiver can exacerbate poverty risks in these cases as these sources of income are terminated (Knijn and Ostner, 2002).

and Mears, 1999; Arber and Venn, 2011, p. 159). Consequently, care-givers can also experience social exclusion due to care-giving constraining their ability to engage in social engagements and leisure pursuits (Walker, 1983; Jenson and Jacobzone, 2000; Jenson, 2004).

The research also highlighted how the burden of responsibility and emotional labour associated with care-giving could have emotional and psychological costs for care-givers. These are noted to include increased physical and mental stress, anxiety, worry, depression, tiredness and associated physical health manifestations (Walker, 1983; Watson and Mears, 1999; Arber and Venn, 2011). For example, the need to think about, be alert to, anticipate and recognise the needs, wants and wellbeing of others could result in the care-giver experiencing concern and anxiety about the dependent person's well-being at every moment of the day, including while at work, and during the night thereby affecting their sleep patterns (Watson and Mears, 1999; Arber and Venn, 2011). The 'emotional labour' required of the care-giver in order to regulate their own emotions and those of the care-receiver, manage inter-personal conflict, and provide emotional support, was also noted to be demanding, exhausting and difficult work (James, 1989, p. 15, 1992; Watson and Mears, 1999). The unpredictability of care could have long-term emotional implications due to care-givers being unable to put a time-limit on how long they will have to provide care for increasingly dependent elderly relatives and also having to come to terms with their relatives decline and death (Ungerson, 1987, p. 66). The emotional legacy of care-giving could also continue to affect carers long after the death of the care-receiver because of painful images of their relative's suffering or feelings of guilt (Arber and Venn, 2011).

The conceptualisation of care as a burden in the mainstream feminist literature has been criticised by other scholars, particularly within the disability literature, on a number of fronts. Firstly, for emphasising only the negative experiences of informal care-giving; secondly for neglecting the care-receivers' perspectives within the care relationship; thirdly for producing a construction of caring that is in itself a form of oppression against disabled people. Morris (1997) argued that the feminist construction of care had conceptualised the care-giver role as one of 'taking responsibility for' and 'protecting' the care-receiver which undermined the empowerment of disabled people and placed them in the position of powerless dependents within the relationship. It had also conceptualised disabled people as burdens who encroach on the freedom and autonomy of those upon whom they are dependent (Dalley, 1996; Barnes, 1997), and therefore blames those people in need of care for the perceived oppression of carers (Calderbank, 2000, p. 530; Oliver et al., 2012). Together this had contributed to the formulation of a disempowering construction of dependency as an undesirable

state and failed to acknowledge the political struggle of disabled people in their long-standing campaign to gain more power, control and self-determination over how their care needs are met (Oliver, 1990, p. 85; Fisher, 1994; Morris, 1997). Moreover, the neglect of the experiences and views of the person being cared for within care research is considered to have contributed to the needs of care-givers being prioritised over those of 'service users' not only in research but also in policy (Barnes, 1997; Swain et al., 2003).

The terminology applied to care-giving within the feminist literature and government policies has also been contested as oppressive. For disabled people, in particular, the term 'care' has become closely associated with paternalistic, oppressive and even abusive care practices (Swain et al., 2003; Barnes, 2012). Feminist scholars have been criticised for having constructed 'caring' to describe what carers feel and do rather than what care-receivers feel and do (Graham, 1993, p. 463), and for associating the term 'carer' with the idea of care as a burden (Molyneaux et al., 2010). Meanwhile the use of the terms 'dependent', 'service user', 'cared for' and even 'care-receiver' to describe the people who are in receipt of care has been criticised because these labels imply passivity and a lack of agency within the care relationship (Mason, 1996; Henderson and Forbat, 2002), which downplays their role as active agents (Barnes, 2012). Both sets of terms are considered to have entrenched these individuals at opposing sides of a situation as completely separate groups with conflicting interests rather than showing them to be sharing a relationship of care (Morris, 1991; Barnes, 1997, p. 112; Molyneaux et al., 2011). The polarised construction of these roles and positions are criticised for not reflecting the complexity, mutuality (Henderson and Forbat, 2002, p. 674), reciprocity (Barnes, 1997, p. 129), and relational nature of caring relationships. Barnes (2012) acknowledges that it is not empirically accurate to define people as only givers or receivers of care. However, she argues against the concept of care being abandoned in favour of terms such as assistance, help or support as suggested by disability scholars (e.g. Finkelstein, 1998; Shakespeare, 2000). She considers 'care' to be the only term which can capture the complexity and ethical application of the process it describes. Moreover Barnes (2012, p. 178) postulates that the disputes between disability and feminist scholars are ultimately caused by the insufficiency of state funding for care services, with carers' needs existing as a symptom of service users' unmet needs by the state (Molyneaux et al., 2011).

### **2.3.4 Care as a relationship**

In order to address the care-giver bias contained in the existing feminist analysis of care some scholars developed broader analytical frameworks which incorporated the perspective of care as a

relational activity featuring both care-givers and care-receivers (Tronto, 1993; Sevenhuijsen, 1998; Williams, 2001, 2004). Tronto's (1993, pp. 106–108) conceptualisation of care shown in Figure 2, which formed the basis of her political argument for an ethic of care, described care as a process consisting of four inter-connected phases. They include: the recognition of the need for care; the assumption of responsibility for responding to the identified need; the direct provision of care; and the response of the care recipient to the care provided. Tronto argued that each phase of the care process needs to be completed in order for care to be fulfilled. This conceptualisation recognised the relational dimension of care as a key aspect of its multi-faceted nature alongside its practical, sentient and moral dimensions (Mason, 1996). It also explicitly acknowledges the care-receiver's active role within the caring process and the need to recognise their experience (Barnes, 2012).

**Figure 2: The four ethical elements of care (Tronto, 1993)**

<b>"Caring about"</b>	The need for care/ attentiveness to care
<b>"Taking care of"</b>	The taking of responsibility for care
<b>"Care-giving"</b>	The daily tasks of tending
<b>"Care-receiving"</b>	The responsiveness to care

The recognition that care occurs within a relationship requires the complex inter-dependencies, interactions and power relations between the care-givers and care-receivers to be taken into account. For care and caring relationships can give rise to inequalities and abuses of power between those involved (Williams, 2004). Waerness (1984) had previously recognised the relational nature of care and constructed three models for analysing the different power dynamics that can be found within different types of care relationship. Even so, it is Tronto's ethic of care framework which provides the tools for considering how the power imbalances found within different types of care relationships can be managed. Waerness' 'spontaneous care model' describes healthy adults who have ties to one another through kinship, friendship, or as neighbours providing reciprocal care and support to one another on a give and take basis. This model reflects a fundamental principle of the ethics of care, which is the recognition that all human relationships contain a care dimension (Tronto, 1993; Barnes, 2011). Meanwhile, Waerness' other models describe care relationships where either the care-giver is situated in a subordinate position to the care-receiver or vice versa. Waerness' applied her 'personal services care model' to describing the non-reciprocal domestic care work that women are forced to undertake on account of their subordinate position within the family (Waerness, 1984). This model is also applicable to those care relationships where the care-receiver

is in a position of financial, social or labour control over the care-giver (Ungerson, 1990; Standing, 2001; Sipilä et al., 2003). For example, where care-receivers employ or pay their care-givers using statutory or private cash transfers, care-givers may be vulnerable to exploitation due to their financial dependency on the care-receiver (Daly and Rake, 2003; Fine and Glendinning, 2005). They may feel compelled to work beyond their contracted hours (Standing, 2001), and in the case of informal care-givers may feel unable to exit from an unsatisfactory employment situation due to the obligations and emotional ties underlying the care relationship. Where the provision of care is extensive the care-giver may also be placed in a position of dependency due to being unable to attend to their own needs (Kittay, 2001). Lastly, Waerness applied her 'care-giving work model' to describe 'caring for dependents', whereby the care-receiver is placed in a subordinate position to the care-giver on account of being unable to manage their own needs without their support (Twigg, 2000, p. 179). This makes care-receivers vulnerable on account of being dependent on someone to feel an obligation or desire to care for them (Waerness, 1984, p. 189); needing support with intimate care tasks which involves nakedness (Twigg, 2000, p. 180); and their wellbeing depending upon the quality of the care provided to them by their care-givers who may be unqualified, unskilled and unregulated (Ungerson and Yeandle, 2007). Moreover, although informal care has often been assumed to provide a superior form of care because people are cared for by those who are familiar to them (Qureshi and Walker, 1989; Thomas, 1993; Ungerson, 1990; Pilj, 2003), the proximity and quality of the personal relationship between the care-receiver and care-giver can have an inhibiting and obstructive effect on the caring process (Ungerson, 1987, p. 121). In the worse cases this can result in unwanted dependency, oppression and abuse of the care-receiver (Waerness, 1984; Qureshi and Walker, 1989; Williams, 2004).

It is important to recognise that care relationships are dynamic. Consequently the power relations between members are '...constantly....(re)negotiated through interaction' (Dominelli and Gollins, 1997, in Larkin and Milne, 2014, p. 28), as well as changing over time as reciprocal care morphs into a more asymmetrical care model. Moreover, multiple sets of power dynamics can occur simultaneously within one care relationship. The disability literature and disability movement has argued that all too often disabled people find themselves subjected to the 'caring for dependents model' in which they are controlled by their care-givers, rather than in control of caring relationships (Macfarlane, 1994; Calderbank, 2000, p. 529). Cash transfer schemes which enable care-receivers to employ their care-giver have therefore been promoted by the disability movement as a way to redress their physical vulnerability (Glendinning, 2008, p. 461) and reduce their sense of indebtedness to informal carers (Ungerson, 2004, p. 206), by granting them choice and control as

care purchasers over how their care needs are met. Even so, Barnes (2012) warns that a care relationship which is controlled by the care-receiver carries similar dangers to those which are controlled by the care-giver. The fact that both members of the caring dyad can experience dependency and a loss of autonomy on account of the other person highlights the need for individuals to be mindful not to abuse each other's vulnerability (Sevenhuijsen, 2003; Rummery and Fine, 2012). Consequently, Waerness (1984) and Barnes (2012) argue for good caring to reinforce the self-sufficiency and independence of the care-receiver, leaving them neither overprotected nor neglected by the care-giver. This requires care-givers to adopt a collaborative 'doing tasks with' approach to care provision, whereby the care-receiver determines what they want to do, when, and at a pace which enables them to actively participate in the task. However the provision of 'good care' entails heavy use of time inputs which can severely limit how care-givers can use their own time (Ungerson, 1983a; Watson and Mears, 1999; Kilkey, 2000; Bittman and Folbre, 2004, p. 3; Wolf, 2004). This can lead to care-givers being tempted to 'do tasks for' the care-receiver or neglecting to complete care tasks adequately which can undermine the care-receiver's wellbeing, skills and abilities in the short and long-term. The ethics of care recognises how there is real potential for abuse of power in care relationships and recommends adopting an inter-relational perspective in order to address these problems. Members of the caring dyad need to ensure that care responsibilities are met in a way which addresses and is responsive to both their needs (Lister, 2003; Barnes, 2012). This requires individuals to have an awareness of their own vulnerabilities as well as an appreciation of the different positioning of others within the care relationship (Mason, 1996; Williams, 2001; Barnes, 2012). Care-givers need to be aware of their need for self-care and take responsibility for that in order to avoid self-sacrifice and burn out as well as being alert to avoiding domination of the care-receiver (Barnes, 2011). This requires a process of flexible negotiation to take place between the care-receiver and care-giver in order to acknowledge each individual's needs and to determine how best to respond to those needs in a way which oppresses neither member (Barnes, 2012).

## **2.4 Care, gender and welfare states**

This final section examines the macro level analysis of care undertaken by feminist scholars which revealed the implications of its gendered construction. This analysis has been essential for understanding the treatment of care by states and explaining the devalued position of care and those associated with the provision and receipt of care within capitalist societies. The feminist literature exposes the links between the cultural construction of gender roles and the institutional location of care and how this has contributed towards a gendered construction of citizenship which

sees social rights awarded to those engaged in paid work rather than those involved in care-giving. The ethic of care proposed by feminist scholars offers a solution to these existing systemic deficiencies and inequalities and provides a comprehensive framework for analysing how states can better support care. However, one limitation of the feminist literature remains that care has primarily been portrayed as a women's issue. This conceptualisation does not acknowledge the diversity of informal care-givers and the fact that all care-givers are negatively affected by the gendered construction of care.

#### **2.4.1 The gendered construction of care and citizenship**

Feminist scholars have revealed the gendered construction of care within capitalist societies and exposed the implications this has had for the position of women in society (Graham, 1983; Daly, 2002). They explained how the gender culture in a society creates cultural constructions of 'femininity' and 'masculinity' which are embedded with expectations and ideas about the normal behaviour and roles of women and men within society (Pfau-Effinger, 1998; 2000; Duncan, 2000). Care-giving has been bound up with the construction of femininity due to the nature of women as mothers being used as evidence of their 'natural' inclination to provide care for family members (Dalley, 1996, p. 17). These cultural beliefs and norms affect who the care-giving role is allocated to within a society, and influence a society's welfare values which determine which institutions are considered the most appropriate providers of care (Daly and Rake, 2003; Pfau-Effinger, 2005). In most industrialised societies the family has been assigned as the key institutional provider of care, and care provision has been constructed as the responsibility of women rather than men (Pfau-Effinger, 2000, p. 267; Leira and Saraceno, 2002). Consequently the household, as the site of this care provision has been constructed as a private, female domain, meanwhile the labour market and state institutions have been constructed as public, male domains (Pateman, 1989). Together, the gender culture and welfare values of a society influence how welfare states treat care, not only through the policies they implement but also their policy absences. In turn state action or inaction can perpetuate the cultural beliefs and norms about gender roles and responsibilities at a household and societal level and reinforce inter-generational obligations and duties (Pfau-Effinger, 2000, 2005). For example, feminist scholars have shown how welfare states can institutionalise rather than alleviate the dependency of both care-givers and care-receivers by failing to provide adequate support for each group's needs (Finch and Groves, 1982; Graham, 1983), thereby reinforcing women's position and oppression within the private sphere (Williams, 1997). In the UK this was evidenced by the implementation of insufficiently resourced community care policies which rely heavily upon families providing informal care (Finch and Groves, 1980, p. 494; Ungerson, 1990;



Dalley, 1996), which together with the ungenerous Invalid Care Allowance payment reinforced the gendered division of labour rather than promoting men and women sharing the work of care and paid work (Baldwin and Glendinning, 1983; Groves and Finch, 1983).

Feminist scholars applied their gender analysis of the activities of care and paid work to exposing how social rights and citizenship in advanced capitalist societies are gendered. They revealed that citizenship is a male prerogative because social rights are primarily constructed for those individuals engaged in the public sphere of paid employment (Pateman, 1989; Woodward, 1997). The positioning of women as care-givers in the domestic sphere had therefore denied them access to full citizenship. To rectify this inequality feminist scholars argued that care needs to be recognised as a social good which actively contributes to upholding the productivity and social reproduction of the labour force; and should be recognised as part of the state's sphere of influence and responsibility and considered a legitimate concern for public policy (Leira, 1990; Leira and Saraceno, 2002; Coffey, 2004). Two separate solutions for de-gendering citizenship were proposed, both of which require social policies to be implemented to enable women to make legitimate choices in relation to accessing citizenship rights (Waerness, 1984; Leira and Saraceno, 2002, p. 56). Women can either be supported to achieve full citizenship status and access social rights in the same way as men, through participating in the labour market, with state funded care services being provided to liberate them from the obligation of providing unpaid care (Knijn and Ostner, 2002, p. 152). Or the activity of care is awarded social citizenship rights of equal value to those attached to the activity of paid employment, with statutory financial support being provided which acknowledges care as a demanding form of work and promotes the financial independence of care-givers (Groves and Finch, 1983, p. 161; Knijn and Kremer, 1997, p. 332). Even so, the concern remained that neither option would overcome the existing patriarchal construction of citizenship. Women would either be treated as lesser men within the public sphere or else would remain confined to the private sphere as care-givers with a lesser citizenship status to those individuals engaged in work (Pateman, 1989). Fraser's (1994) resolution to this dilemma was for a gender 'inclusive citizenship'<sup>12</sup> to be constructed which makes women's life patterns of combining work and care the de-gendered norm. Both men and women would be recognised as having dual roles as both wage workers and unpaid care-givers, and social policies and social rights would be implemented which make the choice between breadwinning and caring costless (Leira, 1992; Fraser, 1994; Knijn and Kremer, 1997; Lister, 2001, 2003; Orloff, 2002). This would require flexibility within the job market to enable people to manage

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<sup>12</sup> Incorporating the 'universal breadwinner model' and 'care-giver parity model',

their dual roles and care provision to be shared across different institutional providers with informal care being remunerated via statutory care allowances.

#### **2.4.2 Contesting the feminist conceptualisation of care as a women's issue**

This feminist analysis was essential for highlighting the inequalities faced by women in society on account of the social construction of care-giving as a female role. However due to the feminist literature primarily focusing their analysis on child care and motherhood (Sevenhuijsen, 1998; Daly and Rake, 2003, p. 19), the greater diversity of individuals undertaking informal care-giving was initially not acknowledged. Consequently the feminist literature contained its own gender bias by conceptualising caring solely as 'women's work' and a women's issue. This overlooked the substantial role that men play in informal care provision (Finch and Groves, 1982; Arber and Gilbert, 1989; Morris, 1991; Russell, 2007; McDonnell and Ryan, 2013). Some of the earlier survey findings<sup>13</sup> which had supported this gender bias were consequently revealed to have been based on unrepresentative samples, poor response rates and ambiguous questions about people's caring roles (Fisher, 1994). Meanwhile, subsequent General Household Survey data revealed just under half of the informal care-givers in the UK to be male,<sup>14</sup> with men over 65 being more likely to provide care than women (Vlachantoni, 2010). Research also showed that marital relationships, co-residency, the quality of people's relationships, their geographical proximity and resources could precede gender as the main determinants for taking on an informal care-giving role, contributing to men being primary care-givers even when female kin are available (Qureshi and Walker, 1989; Finch and Mason, 1990, 1991; Dalley, 1996; Mooney et al., 2002; McDonnell and Ryan, 2013). The feminist literature had also generated a gendered theory of care provision which considered women to be more likely to undertake the 'caring for' role while men restricted themselves to the 'caring about' role or undertaking practical rather than personal care support. These assumptions were also challenged (Fisher, 1994; Russell, 2007). Male carers, particularly among those aged over 65, were found to undertake high levels of intensive and intimate care provision for their spouses (Green, 1988; Arber and Ginn, 1995; Russell, 2007; Del Bono et al., 2009; Vlachantoni, 2010; Schmid et al., 2012), and the provision of personal care is often determined by the gender of the person requiring the care as much as the care-giver (Finch and Mason, 1991, 1990; Arber and Ginn, 1995), due to the taboo nature of these intimate care tasks involving nakedness and touching (Ungerson, 1983b; Twigg, 2000). Informal care cannot therefore be solely recognised as a female activity and women's

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<sup>13</sup> For example, the 1980 Equal Opportunities Commission survey showed three times more women caring than men (Qureshi and Walker, 1989, p. 16).

<sup>14</sup> 1985 and 1992 General Household Survey data found 2.5 million and 42.6% of care-givers in the UK were men respectively (Green, 1988; Fisher, 1994, p. 663).

problem (Fine and Glendinning, 2005). Furthermore, the feminist literature was also criticised on account of not recognising the experiences of all types of female informal care-givers equally, due to the initial focus being on non-disabled, white, middle class women (Graham, 1993; Morris, 1993), and middle-aged women providing filial care to their ageing parents (Arber and Gilbert, 1989; Fisher, 1994; Arber and Ginn, 1995). Consequently the caring experiences of working class women, women from ethnic minority groups and older women were initially overlooked (Walker, 1983; Qureshi and Walker, 1989; Graham, 1991, 1993; Morris, 1993; Fisher, 1994; Williams, 2001; Vlachantoni, 2010). However, it is essential to recognise that the consequences of the gendered social construction of caring is applicable to all carers, whether female or male, of any ethnicity, age and class. All of whom are placed in a vulnerable position due to the lack of value attributed to care in advanced capitalist societies which ensures they are all subjected to the same inadequate statutory protection with managing the risks associated with their care-giving role.

### **2.4.3 Applying an ethics of care to the treatment of care by capitalist states**

The development of the ethics of care by feminist scholars has provided a comprehensive moral and political framework which can be applied at both an individual and societal level to recognising the intrinsic value of care to humanity. This holistic framework addresses some of the aforementioned limitations found within the feminist literature by taking care-receivers into account and not assuming the gender of care-givers to be female. It also sets out the specific ways in which care and those engaged in the provision and receipt of care are to be treated by states through their social policies in order for an ethics of care to be realised. It can therefore serve as a useful tool for analysing how informal care is treated by states.

Feminist scholars argue that capitalist societies currently operate in accordance with an ethic of justice. This sees institutions, democratic practices, public policy decisions and citizenship constructed around legalistic principles that assume the ideal state for individuals is as independent, autonomous, rational, cognitive beings (Tronto, 1993; Williams, 2001; Barnes, 2012). It is argued that this focus has allowed the significance of care to individual and collective well-being to go unacknowledged. It has resulted in: care being devalued and made invisible within capitalist society (Barnes, 2012); dependency being constructed as an undesirable, negative state; and welfare policies being constructed which promote individual rather than collective responsibility for well-being, and promote and value paid work rather than care (Watson and Mears, 1999; Barnes, 2012). Feminist scholars argue that the deficiencies within the current capitalist system can be rectified through the adoption of an ethic of care which serves to compliment rather than replace the ethic of

justice. For both are deemed necessary to achieve social justice at both a personal and political level (Tronto, 1993; Williams, 2004; Barnes, 2012; Rummery and Fine, 2012). The ethic of care requires states to acknowledge the benefits care brings to the whole of society including its function as an important source of social cohesion (Knijn and Kremer, 1997; Williams, 2004; Barnes, 2012). The key principles of the ethic of care which states need to incorporate into their policies and practices include: care of oneself and others being recognised as a universal activity and a meaningful social process affecting all human relationships (Sevenhuijsen, 2003; Williams, 2004); and recognition of the interdependency and relationality of humans and the potential and responsibility we all have to be caring and cared for<sup>15</sup> (Williams, 2001; Barnes, 2012). Tronto (1993, p. 180) set out how an ethic of care could be practised at both an individual and state level by applying the following moral qualities to decision-making about how we manage and negotiate care on a daily basis in our own lives, and how state institutions make judgements about establishing needs and negotiating how those needs can best be met (Williams, 2001; Barnes, 2012). The qualities include: *attentiveness* whereby the needs of self<sup>16</sup> and others for care is noticed; *responsibility* whereby the need for action to respond to the identified need is accepted and the responsibility to care is assumed; *competence* in undertaking care work to ensure good care is provided; and *responsiveness* of the care-receiver to the care provided, which includes the care-giver understanding how receiving care is experienced by the care-receiver from their perspective (Tronto, 1993; Barnes, 2012).

Feminist scholars described how the application of the ethics of care to the treatment of care by states in practice would require states to address the following points. Recognise and treat the right to care, both in relation to the right to receive care and the right to give care, as universal citizenship rights (Williams, 2001; Barnes, 2012). Accept responsibility for ensuring care for their citizens and implement state policies which spread the costs and burdens of dependency more evenly through society (Kittay, 2001). For people's capacity and competence to do care well is noted to be significantly affected by the extent to which care is valued and supported socially and practically (Barnes, 2012, p. 39). Provide appropriate and adequately resourced welfare policies and support which can eradicate the socially created dependency of both the care-receiver and care-giver and enable them to make real choices (Fine and Glendinning, 2005). Such as, carers being free to choose whether or not to care and how to provide care, and care-receivers being free to choose the level and type of care they receive and from whom (Rummery and Fine, 2012). Design state policies which recognise the diversity and particularity of people's needs and situations and seek to address

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<sup>15</sup> This conceptualisation challenges the binary distinction of care-receivers and care-givers.

<sup>16</sup> For it is recognised that a person who does not care for themselves may eventually be unable to care for others.

existing inequalities between different groups rather than reinforcing them (Williams, 2004, p. 10). In relation to this universal statutory provision is argued to be preferable to limiting state protection to low income carers due to the stigmatising and residualising effects this can have (Kittay, 2001). Moreover, design care policies which recognise the complexity and reciprocity of care relationships and empower both care-receivers and care-givers, rather than recognising only one party's needs or risks thereby setting them in conflict with one another (Barnes, 1997, p. 118). This includes state policies recognising that care-givers also need to be cared for to ensure that their own needs do not go unmet and to enable them to continue to care if they wish to do so without disadvantage to themselves (Kittay, 2001; Barnes, 2012). Provide multi-dimensional policies offering 'time, financial and practical support' to care relationships to enable the diversity of their individual needs to be met through a configuration of flexible support options of their own choosing (Glendinning, 1998a; Williams, 2001, p. 487; Ironmonger, 2004; Barnes, 2012). For example, providing care-givers with the right to have time to care; the right to rest and respite; and the right to combine work and caring responsibilities, through the provision of good quality, affordable care services, flexible working policies and care leave from employment (Knijn and Kremer, 1997; Lewis, 2001; Williams, 2001, 2004; Sevenhuijsen, 2003). Additionally, providing statutory cash transfers which offer adequate compensation to care-givers and enable them to make real choices about whether to work or care by making either option cost neutral (Lewis, 2001). Meanwhile providing care-receivers with a right to professional care and collective care provision as well as access to adequate cash payments to enable them to make real choices about how their care needs are met (Knijn and Kremer, 1997; Lewis, 2001; Barnes, 2011).

## **2.5 Conclusion**

This review of the feminist literature and the disability literature has been critical to gaining a comprehensive understanding of the concept of care and its treatment within capitalist society. Both sets of literature will support the development of my conceptual and empirical frameworks discussed in Chapters 3 and 4 and inform the design of my research methodology and analytical frameworks for assessing the treatment of informal care by states. Firstly, the feminist literature brings attention to the need to assess care policies in relation to the extent to which they reveal the state to recognise the different dimensions of care, as a physical, emotional, and relational activity, and the temporal unpredictability of long-term care. Secondly, the importance of the relational nature of care emphasised by disability and latterly feminist scholars highlights the necessity to take the state's treatment of care-receivers as well as informal care-givers into account within any care-related analysis. Thirdly, the critique of the feminist literature on account of its initial bias relating to

gender, class, ethnicity and disability, highlights the need to analyse the extent to which states recognise the diversity of informal care-givers within their care policies. For it is clear that any care-giver may be disadvantaged by the gendered construction of care and the subsequent level of statutory support provided by welfare states. Consequently my methodological framework will incorporate a range of key characteristics in order to reflect the diversity of informal care-givers and assess the treatment of different types of care-givers by state policies. Lastly, the moral principles and social policy practices considered by feminist scholars to demonstrate an ethic of care will support the construction of my analytical frameworks in setting out the scope of the policy environment to be analysed. It will also provide some key criteria against which the treatment of informal care by states policies can be subsequently analysed.

In the next chapter, two key contributions of the feminist literature taken from this literature review will support the development of my conceptualisation of care-giving as a social risk. This includes the consideration of care as a burden for the care-giver and the feminist analysis of the gendered construction of care. However, whereas feminist scholars have tended to focus their attention on analysing and comparing the social rights and citizenship status of care-givers and workers, I will apply this feminist lens to critiquing the social risk literature and using it to explain the differential treatment of social risks by states.

## Chapter 3: Care and Social Risk

### 3.1 Introduction

This chapter provides the theoretical and analytical framework for my thesis based upon the concept of social risk. In this chapter the treatment of the contingency of care, and long-term care in particular, by the social risk literature and states is discussed. The contingency of long-term care consists of two key elements: the long-term care needs of older people; and long-term care provision in the form of formal or informal care provision. The intention of the overall thesis is to analyse the state's treatment of informal care as a social risk, it is not to conduct an additional analysis of the state's treatment of older peoples' long-term care needs as a social risk. However, the inter-relational nature of care makes it necessary to explore how the literature and states treat the risks associated with both these elements of long-term care in order that the treatment of informal care by state policies can be fully understood. For a key way in which states may recognise and seek to protect informal care-givers against the care-related risks which they face is through the provision of statutory support to meet older care-receivers' care-related needs.

The review of the social risk literature exposes how the contingency of long-term care has remained at the periphery of the literature's analysis of how welfare states recognise, treat and manage social risks. Moreover, my own initial attempt to make a case for the long-term care of older people, and informal care in particular, being conceptualised and classified as a social risk highlighted there to be ambiguities and gaps in the theorisation of social risk within the existing literature. The application of a feminist critique to analyse the existing literature exposed the gendered assumptions contained within the existing social risk concept and helped to reveal why welfare states may treat different contingencies and risk-bearers differentially. In order to rectify these oversights I deconstruct the concept of social risk and uncover the distinctive *characteristics* and *processes* which make particular contingencies, social risks. This enables two objectives to be achieved. Firstly, revealing the multi-dimensional characteristics of social risk helps to support my analytical examination of why some contingencies are social risks and how certain risk-bearers may be more vulnerable to experiencing and managing social risks on account of their characteristics. Secondly, the key factors are identified which contribute to the process through which particular contingencies and groups of risk-bearers come to be recognised by states as requiring some form of state intervention and protection. Both elements form the analytical framework which is subsequently used to analyse: whether, and how, states recognise long-term care, and informal care-giving in particular, as a social risk which requires

public support and protection; and the extent to which all risk-bearers who experience this contingency are treated equally. Overall this analysis helps to reveal the changing treatment of long-term care by states over time from being an unrecognised social risk during the post-war era within most industrialised welfare states to becoming a partially recognised social risk during the post-industrial era.

### **3.2 Reviewing the social risk literature**

This section reviews the way in which the concept of social risk has been discussed and utilised in the welfare state and social risk literature. Although the concept of social risk is not clearly defined within the literature, two distinctive features appear to be shared by those contingencies which have been identified as social risks: the individual experiencing the contingency may be placed at risk of financial poverty; and their well-being may be undermined thereby placing them at risk of welfare loss. More often than not these two elements of risk are interlinked, with one contributing to the other.

Many of the contingencies recognised as social risks in the literature, such as homelessness and disability, are recurrent, affecting people across different eras and societies. Meanwhile some are specific to particular socio-economic conditions, the risk of mass unemployment being a product of wage-earning industrial societies (Esping-Andersen, 1999, p. 37). Previously individuals sought protection from these contingencies via the family, community, market and religious institutions, with different institutional configurations being prioritised during different eras and national contexts (Jenson, 2004, p. 3). However, since the nineteenth century the state has incrementally increased its intervention in providing public protection against particular contingencies (Baldwin, 1990, p. 5). This culminated in the founding of welfare states. The state's role has therefore come to be viewed to be of paramount importance for alleviating the poverty and inequality effects faced by those individuals experiencing particular contingencies (Taylor-Gooby, 2004a, pp. 7–8).

The social risk literature makes the dualistic distinction between the state's management of old social risks during the post-war period and how states are responding to the new social risks emerging out of the post-industrial changes affecting advanced capitalist societies. The literature implies that it is only when the state is deemed to have taken explicit responsibility for protecting citizens against particular contingencies that they are classed as a social risk.



### 3.2.1 Old social risks

The literature identifies a multitude of contingencies which were socialised during the pre- and post-war era in order to protect individuals and families against the risks of poverty and welfare loss. These included: hazards such as short-term unemployment, sickness, invalidity, accidental injury, parenthood and widowhood; and life-cycle risks related to insufficient resources during childhood and old age (Esping-Andersen et al., 2002; Bonoli, 2007; Myles, 2002; Baldwin, 1990; Hacker, 2004; Jenson, 2004; Abbott et al., 2006; Huber and Stephens, 2006). It is important to note that most of these recognised 'old social risks' were associated with the public sphere of paid employment, meaning that the recognised risk-bearers at that time were assumed to be male. For example, states recognised the welfare risks inherent in the activity of industrial employment and sought to prevent, or protect against, work-related health problems and injuries by implementing health and safety legislation and industrial accident insurance schemes (Bonoli, 2007; Huber and Stephens, 2006). States also recognised financial poverty risks to be inherent within the capitalist system due to the predominance of the labour market as the primary source of welfare production within industrial society. Consequently, contingencies which acted as barriers to people accessing paid employment such as old age infirmity, disability and unemployment were also recognised as social risks. This led to a range of policies being implemented to protect men's incomes and their ability to provide for their dependent families. For example, in order to manage the risk of unemployment, labour market regulations and Keynesian economic policy interventions were used to promote full employment for men and secure their access to a family wage (Bonoli, 2005, 2007). Decommodifying income maintenance programmes were also implemented to provide financial protection against poverty risks for those men who were unable to work (Baldwin, 1990; Bonoli, 2007). Male earnings were also protected against the eventuality of catastrophic spending through the provision of national health and education services and family allowances.

The explicit objective of the post-war welfare state in the UK was described by Sir William Beveridge to be the 'pooling of risks to protect *everyone* from shared vulnerability to the contingencies of industrial society' (Beveridge 1942, in Kemshall, 2001, p. 27).<sup>17</sup> However, despite this claim that post-war states would uphold the wellbeing of society as a whole by providing inclusive risk protection to all (Hacker, 2004, p. 249), it is clear that the policy interventions of most states only extended to recognising the need to protect specific groups of individuals from particular contingencies. The welfare state literature explains how the aforementioned contingencies came to be recognised by states during the post-war period as requiring social protection due to political

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<sup>17</sup> *My emphasis.*

mobilisation of working-class men who successfully campaigned for social rights to a secure income and an adequate standard of living for themselves and their families (Esping-Andersen, 1999; Edwards and Glover, 2001; Myles, 2002; Bonoli, 2005, 2006).<sup>18</sup> This explanation is helpful for understanding the paid employment bias and gendering of those social risks recognised by states at that time. However, the literature does not go on to acknowledge that other social risks may also have existed during this period which were not recognised by states due to them affecting other types of risk-bearers. The lack of gendered analysis in the social risk literature reveals a fundamental weakness in its ability to provide a comprehensive conceptualisation of social risk.

### **3.2.2 New social risks**

The literature uses the term 'new social risks' to describe the types of insecurity, social needs and demands which exist in post-industrial economies but which were extremely marginal, if indeed they existed at all, during the post-war period (Esping-Andersen, 2002; Taylor-Gooby, 2004b; Bonoli, 2005). These risks are arising due to post-industrial changes affecting the welfare production of labour markets, families and welfare states. States are responding to the emergence of these new risks and risk-bearers through expanded social policy provision in some areas (Bonoli and Natali, 2012). Meanwhile, states are retrenching more traditional areas of welfare provision for cost containment purposes, leading to the re-emergence of certain old social risks (Ebbinghaus, 2012).

#### **3.2.2.1 Labour market changes**

Over the past few decades advanced capitalist economies have undergone a major transition. Their declining industrial manufacturing sectors have been replaced by knowledge-based service sectors which are characterised by uneven and limited productivity and growth, increasing wage inequalities and job insecurity (Hacker, 2004, p. 249). Moreover, a significant proportion of service sector employment, such as catering, cleaning and care-giving, is low skilled, low paid, insecure, with little opportunity for skills development and training (Gallie, 2002; Jenson, 2004; Bonoli, 2005). The changing nature of the labour market is leading to 'new' contingencies emerging including precarious employment, long-term unemployment and working poverty. These contingencies are leaving unskilled and low skilled workers at risk of entrapment in marginalisation and poverty, with many working-aged adults stuck in the low pay-no pay cycle (Esping-Andersen, 1999, 2002; Jenson, 2004; Taylor-Gooby, 2004a,b; Bonoli, 2005, 2006, 2007). States are attempting to address these

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<sup>18</sup> Baldwin (1990) acknowledges that this explanation underestimates the greater diversity of risk-bearing and claims-making groups found across different national contexts during this period and highlights the role also played by peasants, farmers, catholic parties and the middle classes.

risks through the implementation of wage supplementation policies targeted at the working poor (Bonoli and Natali, 2012); and activation policies which promote labour market participation and human capital formation among adults (Knijn and Ostner, 2002; Jensen, 2011; Bonoli and Natali, 2012). In considering those most at risk of experiencing these new labour market risks, the social risk literature focuses its attention on those risk-bearers who previously had access to life-long, decently paid, manual jobs, i.e. men. It is feminist scholars who point out that women form a key group of these new social risk-bearers. A significant proportion of service sector employment and female labour market participation derives from the unpaid domestic work formerly undertaken by women in the household which has now transferred across to the formal employment sector (Häusermann and Siebel 1995, in Pfau-Effinger, 2000, p. 23; p.265). Added to which the ongoing social and cultural construction of these roles as a female pursuit ensures they are assigned a low social and economic value (Jenson and Jacobzone, 2000; Lewis, 2001; 2006; Jenson, 2004; UNRISD, 2010).

### **3.2.2.2 Family changes**

Where women are recognised by the social risk literature to form a key group of risk-bearers is in relation to the newly recognised social risk of reconciling work and care (Esping-Andersen, 2002; Bonoli, 2005; Bonoli and Natali, 2012). This contingency is noted to have arisen due to women's increased labour force participation (Esping-Andersen, 2002, p. 2); changing labour market conditions increasing the poverty risks faced by low income families leading to the need for two parental earners in order to maintain a satisfactory family income (Jenson, 2004, p. 5); and the emergence of more diverse and less secure family units, including lone parent families (Hacker, 2004, p. 249). Working mothers in particular, who generally have the main responsibility for organising and co-ordinating family care (Ungerson, 1987; Bang et al., 2000; Jenson and Jacobzone, 2000), are also recognised to be at risk of welfare loss, including reduced leisure time and high levels of stress, as they attempt to manage the time pressures of reconciling their work and caring roles (Jenson, 2004; Bittman, Fast, et al., 2004; Bonoli, 2005; Taylor-Gooby, 2004a). Welfare states are increasingly recognising this new social risk through the provision of more affordable child-care services and implementation of parental leave policies (Bonoli, 2007, 2005; Esping-Andersen, 1999; 2006, 2004a; Bonoli and Natali, 2012). The literature also recognises mothers to experience longer term risks as a result of their interrupted labour market participation (Esping-Andersen, 1999, 2002; Taylor-Gooby, 2004a; Bonoli, 2005). This includes individuals' skills and qualifications becoming obsolete thereby affecting their employment reintegration and progression (Taylor-Gooby, 2004a); and insufficient social security contributions being accumulated resulting in lower pension

entitlements (Daly, 2000; Bonoli 2003, in Bonoli, 2005, p. 435). However, the literature focuses almost entirely on the risks that mothers face in relation to child care rather than recognising that these poverty and welfare risks affect *all* care-givers who are attempting to reconcile their work and caring roles.

### **3.2.2.3 Welfare state changes**

Within the new social risk literature Kananen et al. (2006, p. 84) make a useful analytical distinction between what they term the primary social risks associated with labour market changes, and those secondary risks which are derived from policy developments. This is helpful for revealing how welfare states as institutions not only protect individuals from social risks but can also shape the production and distribution of social risks. The literature recognises that secondary risks may arise due to the emergence of new social risks which fail to be addressed by existing social policies (Hacker, 2004, p. 244). For example, income transfers and services based on universal and non-contributory principles are noted to be better placed for protecting groups of new social risk-bearers with fragmented career trajectories from poverty risks than those based on social insurance principles (Esping-Andersen, 1999; Timonen, 2004; Bonoli, 2006, 2007). Secondary risks are also being produced by welfare state retrenchment strategies, particularly in the area of pensions and unemployment, as states seek to manage the fiscal pressures emanating from post-industrial social, economic and demographic changes (Bonoli and Natali, 2012; Ebbinghaus, 2012). States are attempting to contain public expenditure by promoting the individualisation of responsibility for risk-bearers and privatisation of risks (Hacker, 2004; Whelan and Maitre, 2008; Ebbinghaus, 2012). Consequently the state's role is increasingly being substituted with market or family based solutions (Crouch and Keune, 2012). Meanwhile, the generosity of existing statutory schemes are being reduced (Häusermann, 2012), and state resources are being increasingly targeted on a declining portion of the risks faced by citizens and at the most vulnerable risk-bearing groups (Hacker, 2004; Myles and Pierson 2001, in Taylor-Gooby, 2004a; Kananen et al., 2006). The residualisation of statutory protection is allowing old social risks, such as old age poverty, to re-emerge for certain groups of old social risk-bearers (Ebbinghaus, 2012), whilst compounding the poverty risks faced by new social risk-bearers who are simultaneously exposed to both the primary and secondary risks associated with post-industrial changes.

### **3.2.3 Understanding the treatment of long-term care by states and the literature**

The gender blind approach adopted by most social risk scholars and the analytical lens through which they have conducted their welfare state analysis has resulted in a disproportionate focus being placed by the literature on analysing the state's role in the management of poverty risks (Jenson, 1997, p. 184), and the risks associated with paid employment (Hacker, 2004, p. 249). For even where child care is included in the analysis this is due to it being recognised as a barrier to paid employment. Consequently, a comprehensive analysis of the contingency of long-term care, both in terms of the need for long-term care in old age and the provision of informal care to older people, is missing from the social risk literature.

Meanwhile my own initial attempt to classify long-term care according to the old and new social risk dichotomy provided by the literature also proved to be problematic due to finding long-term care to straddle this analytical division. For I considered it to exist as an 'old social risk' during the pre- and post-war era, albeit one which remained unrecognised by most states, but also to be partially recognised by states as a new social risk during the current post-industrial era. However, by applying the feminist construction of the public-private dichotomy to this social risk analysis helped to explain why states do not recognise all contingencies as social risks and do not offer social protection to all risk-bearers; and the marginalised position that the contingency of care has had within the social risk literature. For the predominant location of most of the social risks recognised by states and the literature is the sphere of paid employment. This is the domain which feminist scholars argue has been constructed as a male domain and an arena deemed suitable for public policy intervention (Fraser, 1989). Meanwhile the predominant location of the contingency of long-term care including informal care-giving, is within the private sphere of the household, which is constructed as a female domain and one which is private, personal and intentionally kept free from statutory intervention (Fraser, 1989).

Consequently during the post-war period, with the exception of some Nordic countries,<sup>19</sup> neither the long-term care needs of older people nor the activity of informal care-giving were recognised as contingencies requiring state support. Instead it was deemed to be the prerogative of the family to manage these contingencies, with women ascribed the activity of informal care-giving as part of

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<sup>19</sup> Nordic states constructed care as a public concern from early on in the development of their welfare state systems. Informal care-giving was treated as a form of paid work which helped to protect informal carers against the risk of poverty, and the caring dyad were protected against welfare risks through the implementation of universal public care services (Anttonen and Sipilä, 1996; Jenson and Jacobzone, 2000; Timonen, 2004).

their social role. Even so, the care-related risks experienced by different types of informal care-givers were treated differentially by states. During this period the male breadwinner–female care-giver industrial family model (Pfau-Effinger, 2005) was a key risk management and welfare production system. Although married care-givers were not provided with direct state protection against the risk of poverty associated with their care-giving role, it was assumed by states that both they, and the family members they cared for, would be able to derive financial protection via the male breadwinner’s accrued social rights (Lewis, 1992; Pfau-Effinger, 2005). These entitlements had been designed to ensure that men were capable of financially sustaining the family unit whether or not they were economically active (Jenson, 1997). However, the poverty risks faced by single, divorced and widowed female care-givers and male care-givers, which were exacerbated due to their care-giving role acting as a barrier to paid employment, remained unrecognised. The ensuing lack of state intervention ensured that their risks remained privatised. Meanwhile, the domestic location of care arguably contributed to the lack of recognition shown by most welfare states to the welfare risks associated with the activity of care-giving. Consequently most post-war welfare states remained service lean (Lewis, 1992; Esping-Andersen, 1999; Taylor-Gooby, 2004b). Although health care needs were recognised through the provision of health care services, these were designed to deal with acute phases of illness not to assist dependent people long-term (Pavolini and Ranci, 2008, p. 246). Moreover, the function of existing public care services was to provide institutional care as a last resort for destitute older people once family alternatives and financial means were exhausted (Jenson and Jacobzone, 2000). Care services were not intended to provide support to informal care-givers and protect them against welfare loss by substituting for them in their care-giving role.

Long-term care has been described by some scholars as a new social risk (Jenson, 2004; Taylor-Gooby, 2004a; Bonoli, 2005, 2007), and the provision of elderly care services has been used as an example of a new social risk policy (Bonoli and Natali, 2012; Häusermann, 2012). However, a thorough analysis of long-term care as a new social risk is not undertaken by the social risk literature. This is despite the fact that during the post-industrial era demographic, social and labour market changes are extending and intensifying the risks associated with the need for, and provision of, long-term care. This is contributing to many states at least partially recognising these contingencies as ‘new social risks’, as evidenced by the increasing number of care policies being implemented which are aimed at supporting dependent older people and their informal care-givers (Frericks et al., 2014). With Daly and Standing (2001, p. 2) considering states to have moved from treating care as a “wholly private” social good to treating it as a “partly private/ partly public” good.

### **3.3 Conceptualising social risk**

Applying the feminist analytical lens of care to this social risk analysis helps to generate new perspectives in relation to the conceptualisation of social risk itself. The difficulties I encountered in attempting to analyse the treatment of long-term care as a social risk helped to expose a number of ambiguities and gaps in the existing conceptualisation of social risk set out in the literature. Firstly, the literature has adopted a selective approach towards social risk by only incorporating those social risks into the analysis which have been fully recognised by welfare states, meaning that some form of substantive policy implementation has been undertaken. However, I argue that social risks can exist even if they remain unrecognised by states. Secondly, the literature does not acknowledge that even among those social risks which are recognised by welfare states, different groups of affected risk-bearers may be treated by state policies differentially. The unevenness of states' recognition and treatment of social risks and risk-bearers helps to illustrate how welfare states not only offer protection to certain groups of citizens but can also sustain social risks for other groups which can have significant implications for their wellbeing. By shaping welfare production and affecting the distribution of risks in this way states can therefore produce inequalities among groups of risk-bearers.

In order to make the case for long-term care, in particular informal care-giving, being categorised as a social risk, a two stage process will be undertaken. Firstly, in this section the analytical framework is constructed. This involves deconstructing the concept of social risk in order to expose its individual characteristics and multi-dimensional nature; and identifying the key factors underpinning the political process which lead to contingencies becoming recognised as social risks by states. Secondly, in the final section of this chapter, this analytical framework is applied to analysing and categorising the contingency of long-term care as a social risk.

#### **3.3.1 The characteristics of social risk**

Figure 3 sets out the key constituent characteristics of social risk which contribute towards particular contingencies becoming social risks.

**Figure 3: Characteristics of social risks**

<p><b>Universality of risk</b>  A shared risk across society  Everyone has the chance of being affected by these contingencies</p>
<p><b>Predictability of risk</b>  The degree of regularity with which people across society are affected</p>
<p><b>Unpredictability of risk</b>  The unpredictability of people being affected at an individual level</p>

Social risks are universal in nature, meaning that in principle everyone, no matter what their situation, has the chance of being affected by a particular contingency. Esping-Andersen (1999, p. 37; 40–41) describes this as the ‘democratic risk’ characteristic, and uses the example of old age infirmity which we are generally all at risk of experiencing, as an illustration. Consequently, social risk also contains the characteristic of predictability at a societal level due to the degree of regularity with which individuals within an entire population are affected by particular contingencies during their lifecycle (Powell and Hewitt, 2002, p. 150). However, at an individual level it is evident that not everyone will actually experience some, or indeed any, social risks (Spicker, 2001). This requires the characteristic of unpredictability to also be incorporated within the analytical framework. Even so, certain population groups who share particular characteristics have a higher risk of experiencing social risks than others groups (see Figure 4). These at-risk groups also face an increased vulnerability to experiencing poverty and welfare loss in the event of experiencing a social risk due to their particular characteristic. Each of these higher risk characteristics will now be explored in turn.

**Figure 4: Higher risk characteristics**

<b>Socio-economic status</b>	Class-based risks
<b>Age</b>	Immediate life-course risks
	Extended life-course risks
<b>Relational/familial characteristics</b>	Relational status risks E.g. Marital status
<b>Gender</b>	Gendered risks



### **3.3.1.1 Class-based risks**

Esping-Andersen (1999, p. 37; 40–41) used the term class-based risks to describe how social risks are unevenly distributed across the social strata, their incidence being concentrated amongst lower socio-economic groups who are at increased risk of experiencing particular contingencies. For example, blue collar workers are more prone to occupational injury and have been more vulnerable to the risk of unemployment than white collar workers (Baldwin, 1990; Esping-Andersen, 1999). Socio-economic status can also affect the availability of resources that people have for managing or alleviating the contingency befalling them (Baldwin, 1990, p. 14). Moreover, these class-based poverty risks can be perpetuated both within families and across generations (Esping-Andersen, 1999).

### **3.3.1.2 Life-course risks**

The term 'life-course risk' is used within the social risk literature to describe the increased likelihood of experiencing poverty and welfare loss during particular life-stages. I make the distinction between the *immediate* life-course risks described by Esping-Andersen (1999, p. 41), which are the current poverty risks experienced by groups of the population during the periods when they are not attached to the labour force, such as retirement and unemployment. Whereas *extended* life-course risks describe the poverty risks accrued by individuals during one life-stage which have an extended impact on other life-stages. For example, fragmented employment histories can lead to poverty risks in old age due to insufficient pension contributions (Bonoli, 2007). This type of risk may also be a secondary risk, generated by welfare states due to their choice of policy intervention. For example, individuals in countries with universal flat rate pension schemes are less likely to experience these extended life-course risks (Timonen, 2004; Bonoli, 2007).

### **3.3.1.3 Relational risks**

Relational risks describe how an individual's personal circumstances, including their marital status or familial characteristics, can increase their vulnerability to experiencing poverty and welfare risks. The social risk literature only recognises this type of risk in relation to single parent families (Esping-Andersen et al., 2002; Bonoli, 2007). I argue that individuals with single marital status experiencing any social risk can face an increased risk of financial hardship due to not having the added financial protection of a spouse or partner to fall back on.

### 3.3.1.4 Gendered risks<sup>20</sup>

Gender is an overarching risk characteristic due to it having the ability to compound the existing class-based, life-course and relational risks experienced by individuals. For example, life-course risks are significantly gendered due to women being more likely to take time out of the labour market to provide care. In relation to class-based risks, women form a significant proportion of those engaging in more insecure, low paid servicing work. Meanwhile, in terms of relational risks, single parent households are most likely to be headed by mothers. In some welfare systems women have also been noted to be more prone to experiencing secondary risks due to tending to access social protection as dependent clients via less generous, means-tested, social assistance programmes, while men have had greater access to more generous social insurance schemes as rights bearers (Fraser, 1987; Sainsbury, 1996; Lister, 2003). Consequently, certain groups of women may therefore have an increased vulnerability to experiencing poverty risks and welfare loss.

### 3.3.2 State recognition of social risks

Figure 5 demonstrates there to be a number of factors which contribute towards the process whereby a social risk becomes formally recognised by the state as requiring some form of statutory intervention. Some of these factors are reliant on states determining whether particular contingencies are severe enough to warrant public intervention. Other factors recognise the agency of risk-bearers using political processes to campaign for statutory recognition of particular contingencies. The question as to whether all these factors need to be present simultaneously in order to galvanise state policy intervention or whether different factors can be weighted according to their significance to this process remains beyond the remit of this thesis to pursue further.

**Figure 5: Factors contributing to the recognition of social risks by states**

Threats		Benefits		Political Agency
Scale	Institutional Failure	Social Good	Economic Good	Claims-making

<sup>20</sup> Similarly ethnicity could also be categorised as an overarching higher risk characteristic due to it compounding the existing class-based, life-course and relational risks experienced by individuals. However my thesis does not explore this characteristic further.

### **3.3.2.1 Threats**

The inter-related threats of scale and institutional failure are key factors for why certain contingencies become recognised and socialised. Esping-Andersen (1999, p. 37) notes that state intervention can be triggered if the scale of particular problems are seen to affect growing numbers of citizens to the extent that the welfare of society as a whole is placed at risk. The threat may be related to social, economic or political instability arising out of socio-economic and political inequalities which states seeks to redress through social policy interventions (Baldwin, 1990, p. 5; 21). The threat of institutional failure which occurs when welfare-producing institutions become constrained in their capacity to protect individuals and families against the risks they face can also galvanise state action (Esping-Andersen, 1999; Taylor-Gooby, 2004a). For example, in relation to the family it could be argued that the growing complexity and longevity of people's lives within industrialised and post-industrialised societies is leading to "the risks and contingencies of family life (being) beyond the capacity of most of them to finance adequately from their own resources" (Leonard Marsh 1943, in Jenson, 2004, p. 1). Meanwhile, although individuals may seek to manage their risks privately via the market, private insurance is often only available to insure against 'good' risks rendering the 'bad' risks of those individuals occupying high risk strata uninsurable (Esping-Andersen, 1999, p. 38). States may therefore elect to compensate for large scale institutional failure by using their unique institutional position to redistribute risks and resources more equitably across population groups in order to reduce the risk of societal harm and instability.

### **3.3.2.2 Benefits**

States may also decide to recognise and socialise particular contingencies if they class them: either as social goods due to perceiving them to offer benefits to society as a whole; or as economic goods whereby state intervention would serve to benefit the economy. For example, states may implement social investment strategies including education policies and services to develop children's learning and human capital in order to secure the reproduction of the work force long-term (Daly, 2001; Lewis, 1992; Thévenon, 2011; Jenson, 2012). Meanwhile, child care provision has been used as a policy tool to incentivise maternal employment and promote fertility and population replacement rates (Daly, 2001; Daly and Rake, 2003; Jenson, 2012).

### **3.3.2.3 Claims-making**

Claims-making is the one area where the risk-bearers themselves can actively pursue state recognition of, and protection against, the risks that they face. The social risk literature discusses

how the effectiveness of the claims-making undertaken by risk-bearing groups has varied across the industrial and post-industrial eras. Bonoli (2005, p. 433) notes how the homogeneous group of industrial workers who had access to the political process via political bodies who represented their interests, such as labour movements and social democratic parties, played a critical role in old social risks coming to be recognised by states. The universal nature of many of the contingencies which working-class men sought protection against also ensured that their claims appealed across class boundaries, thereby facilitating the consensus building and intra- and inter-class solidarity required to achieve political recognition (Baldwin, 1990; Taylor-Gooby, 2004a).

In contrast the claims-making potential of new social risk-bearers is noted to be undermined by their heterogeneity and fragmentation. This may serve to explain the unevenness of state responses as to which new social risks are recognised and which risk-bearers are protected through statutory interventions. Taylor-Gooby (2004a,b) and Bonoli (2005) both note that new social risks generally apply to smaller minorities and subgroups during more transitory phases of the family life-cycle i.e. child-rearing, labour market entry or old age dependency. These contingencies are noted to generate new constellations of interests which cross-cut old social risk constituencies based upon traditional class and party structures. The ability of these risk-bearing groups to develop the legitimacy, support and electoral influence needed to implement the policies that would serve their interests is undermined by their lack of coordination, solidarity and power. Bonoli (2005, p. 440) considers this political weakness to stem from the diversity of the risks they experience and their lack of dedicated representative outfits. Their more limited power resources also make them less resistant to competing against claims made by stronger groups of old social risks-bearers, such as pensioners (Bonoli, 2006, pp. 14–15). Consequently they may become more reliant on forming alliances with more powerful actors such as trade unions and employers (Timonen, 2004; Bonoli, 2005, p. 433), who may co-opt or subvert their claims to suit their own economic interests (Taylor-Gooby, 2004a; Hutter, 2006). Moreover, successful claims-making also requires states to be receptive to the demands being made. With Hacker (2004, p. 246) noting that political actors may overtly or covertly oppose expanded state responsibility, particularly during an era characterised by welfare state retrenchment (Beland, 2010).

### **3.4 Long-term care as a social risk**

In this final section I make the case for the contingency of long-term care being categorised as a social risk. To achieve this I demonstrate how the long-term care needs of older people and the activity of informal care-giving present both poverty and welfare risks to risk-bearers. I also consider

the unique risk characteristics of long-term care, relating to its temporal and relational dimensions, which are essential for understanding informal care as a social risk. The analytical framework set out in Figures 3, 4 and 5 is subsequently applied to justify this argument and statistical and empirical evidence is used to illustrate key points.

### 3.4.1 The risks associated with long-term care and their inter-related nature

A substantial amount of evidence exists which supports the contingency of long-term care being considered a poverty and welfare risk to those individuals requiring and providing care. However, the risks associated with long-term care contain a unique dimension which sets this contingency apart from other social risks. This relates to the inter-dependence of the members of the caring dyad. Both members of the caring dyad experience separate risks derived from their different roles and experiences within the care relationship. However, Figure 6 reveals how each individual's poverty and welfare risks are inter-related, and impact on, and exacerbate, one another's risks. Moreover, the unpredictability of the onset, duration and intensity of care needs and care provision can make the financial and time poverty risks associated with care difficult to ascertain and manage.

**Figure 6: The inter-relatedness of care-related risks**

		Poverty risks	Welfare risks
<b>Risk-bearer</b>	<b>Care-giver</b>	<b>Decreased income:</b> Inability to access labour market Extended poverty risks into old age	Lack of leisure time
			Social isolation
			Physical and mental health problems
		<b>Increased expenditure:</b> Care-related costs Covering expenses of care-receiver	Exploitation
	Loss of self determination		
	<b>Care-receiver</b>	<b>Decreased income:</b> Re-emergence of old age poverty due to pension changes Risks related to privatised pension provision	<b>Under-provision of care:</b> Unmet need Neglect (potentially death)
<b>Over-provision of care:</b> Loss of independence and ability Loss of self determination			
<b>Increased expenditure:</b> Care-related costs Covering expenses of care-giver		<b>Inappropriate provision of care:</b> Lack of dignity Abuse	

The activity of care-giving as well as the need for care are associated with increased exposure to the risk of poverty (Glendinning, 1992; Carers UK, 2008). One reason is because the disability-related needs of older people and the activity of care-giving can incur extra costs (Jenson, 2004, p. 16; Glendinning et al., 2009, p. 18; 61). This expenditure can relate to: higher heating bills; special dietary requirements; extra laundry due to incontinence problems; medication; transportation costs; telephone bills from liaising with health and care services; and increased expenditure on labour-saving and time-saving products (Glendinning, 1992, p. 70; Graham, 1999; EUROFAMCARE Consortium, 2006, p. 115; Fry et al., 2011; Carers UK, 2014a). These costs can create inter-related and inter-generational poverty risks, particularly between members of the caring dyad living in co-resident households. Informal care-givers may also find their financial security undermined due to their care-giving role acting as a barrier to labour market participation. This can lead to reductions in their current and future income due to affecting their earnings levels, pension contributions and career progression.

Informal care-giving can also cause welfare loss by placing individuals at risk of experiencing a range of injuries (Carers UK, 2004, p. 5; Lundsgaard, 2005, p. 31) and health problems, particularly psychological problems (Glendinning et al., 2009; Tommis et al., 2009; The NHS Information Centre, 2010a; Arber and Venn, 2011; Milne et al., 2013),<sup>21</sup> although physical health impacts are less conclusive (Young et al., 2006; Pickard, 2007; The NHS Information Centre, 2010a; Vlachantoni et al., 2013).<sup>22</sup> Even so, the prevalence of care-givers reporting good health status is shown to decline as care intensity increases (Vlachantoni, 2010; Milne et al., 2013) and when high levels of care are provided for a long-term duration (Fry et al., 2011). Informal carers have also been found to neglect their own health on account of their caring role which can contribute to their own existing chronic health problems deteriorating (Tommis et al., 2009). Experiencing injuries and health problems may also affect the ability of working-aged care-givers to continue to work (Milne et al., 2013) or re-engage in paid employment, thereby increasing their poverty risks. Moreover, the time poverty risks associated with care-giving, including when reconciling work and caring roles, can contribute to welfare loss: by generating stress for carers (Pickard, 2007; Tommis et al., 2009); and undermining their ability to maintain their own social life and participate in leisure activities (Fry et al., 2011).

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<sup>21</sup> Care-givers reported experiencing: depression and anxiety; tiredness and exhaustion; and feeling stressed and irritable. Moreover, individuals combining full-time work with a caring role had a significantly higher consumption of anti-depressant drugs and tranquilizers than individuals engaged in full-time work only (Schmitz and Stroka, 2013).

<sup>22</sup> For example, care-giving had negative effects on physical health in cases where carers are engaged in dementia care and experience psychological distress (Pinquart and Sørensen, 2007). However the physical health of carers without a chronic condition remained stable (Tommis et al., 2009).

Meanwhile, the older person in need of care is also at risk of welfare loss due to their physical or mental frailty making them dependent upon the help of another person to meet and manage their welfare needs. Without adequate care they are at risk of extensive welfare loss which in the worst case scenario could result in death. Moreover, the inter-related nature of the caring dyad's risks means that if care-givers experience financial or time poverty risks or welfare loss, this may compromise their ability to provide high quality and emotionally supportive care. This in turn can have negative repercussions for care-receivers' wellbeing, with several studies noting a potential link between care-giver exhaustion and the incidence of elder abuse (Glendinning et al., 2009; Smith et al., 2011).<sup>23</sup>

### **3.4.2 Applying the characteristics of social risk to the case of long-term care**

#### **3.4.2.1 Long-term care as a universal risk**

Empirical evidence supports the case for both the need for long-term care and the provision of informal care being categorised as a universal risk due to the degree of regularity with which these contingencies arise within post-industrial societies. Increasing life-expectancy is leading to unprecedented numbers of people surviving into old age (Vlachantoni et al., 2013). On average 26 per cent of industrialised countries' populations will be aged over 65 by 2050, with ten per cent reaching advanced old age i.e. over 80 (United Nations Economic and Social Affairs, 2010).<sup>24</sup> It is this older age group which is most at risk of severe disability. Data from the Survey of Health, Ageing and Retirement in Europe (SHARE) and the English Longitudinal Study of Ageing (ELSA) show steep age gradients in the prevalence rates of many chronic diseases and increased limitations in mobility and activities of daily living (Mackenbach et al., 2005; Marmot and Stafford, 2010, p. 4). More people are therefore facing the risk of surviving many years with functional restrictions and activity limitations, resulting in growing numbers of older people requiring long-term care support (Eurostat, 2011; Vlachantoni et al., 2011, p. 2).

In terms of the universality of the contingency of informal care-giving, the majority of dependent older people in OECD countries continue to rely on informal care to meet their care needs (Jenson and Jacobzone, 2000, p. 28). Of the two million older people with functional disabilities living in private households in England, it is estimated that approximately 85 per cent receive some form of

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<sup>23</sup> Informal care-givers who had physical health problems perceived care-receivers to be unreasonably demanding and experienced an increase in depressive symptoms which was linked to a decline in respectful care-giving and increases in abusive behaviour (Smith et al., 2011).

<sup>24</sup> Calculation undertaken based on data for sixteen OECD countries.

informal care (Pickard et al., 2007).<sup>25</sup> These percentages are anticipated to remain relatively stable over the next 25 years (Pickard et al., 2012). The 2011 census data for England show 10.2 per cent (5.4 million individuals) of the overall population provide at least one hour of informal care per week, with 3.8 per cent providing 20 hours or more (Office for National Statistics, 2013a). The total number of informal carers is expected to increase as the projected population of people with disabilities aged 75 and over increases by 85 per cent by 2032 (Pickard et al., 2012).

Meanwhile, population ageing and post-industrial social changes are leading to fewer members of the younger generation being available to take on the care of dependent older family members (Jenson, 2004, p. 17; Glendinning et al., 2009; European Commission, 2010, p. 22; Carmichael et al., 2010, p. 189). Consequently, informal caring is likely to increasingly feature within the life-course of a wider range of people (Barnes, 1997, p. 114). No matter what an individual's occupational status, wealth, or social situation (Maher and Green, 2002; Jenson, 2004; Kitschelt and Rehm, 2006), gender, age, or marital status, they may find themselves needing to provide care to another individual at some point in their lives. Men will become increasingly more involved in the provision of informal care (Russell, 2007). Sons will increasingly care for their ageing parents due to changes in marriage patterns, their tendency to live at home for longer, and fewer men in their fifties and sixties being engaged in employment (Glendinning, 1992; Mooney et al., 2002, p. 14). Growing numbers of informal care-givers will also feature among older age groups (Lundsgaard, 2005; Vlachantoni et al., 2013). This is due in part to increasing numbers of retired spousal care-givers due to improvements in male mortality (Pickard et al., 2007; Pickard, 2008; Glendinning et al., 2009), and many filial care-givers being over retirement age at the onset of their care-giving responsibilities for increasingly elderly parents (Pickard et al., 2007). Grundy (2005, p. 252) also acknowledged that future cohorts of older people will have later family building patterns, which arguably could lead to increasing numbers of filial care-givers taking on a caring role at a younger age and attempting to manage the triple roles of work, child care and informal care. Increasing divorce rates and childlessness amongst younger cohorts may in time also increase the need for filial care-givers or non-family support due to a lack of spousal or filial support respectively (Grundy, 2005, pp. 251–252; Pickard, 2008; Ní Bhrolcháin and Beaujouan, 2011; Pickard et al., 2012).

#### **3.4.2.2 Higher risk groups**

Although it remains unpredictable as to which individuals and families will be affected by the contingency of long-term care, it is clear that certain population groups experience a higher risk of

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<sup>25</sup> Based on PSSRU model estimates using General Household Survey (GHS) data from 2001/2.



both needing and providing care than others, and face increased risks of poverty and welfare loss as a result of their characteristics.

### ***Immediate life-course risks***

Retired care-receivers and care-givers may experience immediate life-course risks in relation to financial poverty, for most state retirement pensions are unlikely to provide sufficient funding for most long-term care situations (Lundsgaard, 2005). Older people from lower socio-economic groups face re-emerging poverty risks due to the decreasing value of state pension entitlements which are often insufficient to cover even peoples' basic needs in old age (Esping-Andersen, 2002; Myles, 2002; Timonen, 2004). Meanwhile, older people with access to private pensions face financial insecurity risks due to their pension income not being guaranteed (Age Concern and Help the Aged, 2009). Older care-givers are also at increased risk of experiencing welfare loss due in part to often providing more intensive care provision (Maher and Green, 2002; Pickard, 2007; EUROFAMCARE Consortium, 2006; Pinguart and Sörensen, 2007; Vlachantoni, 2010; Vlachantoni et al., 2013). ELSA data show that the number of hours spent caring increases steadily with age (Marmot and Stafford, 2010, p. 4), with care-givers aged over 65 being more likely to provide over 20 hours of care a week than younger age groups (The NHS Information Centre, 2010a). Moreover, older carers may also be at risk of experiencing a deterioration in their own health status leading them to require care in their own right (Attias-Donfut et al., 2008, p. 181). They may therefore face conflicting demands between protecting their own health and the health of the person they care for (Jenson and Jacobzone, 2000; Tommis et al., 2009).

Working-aged care-givers also face immediate life-course risks in relation to poverty due to their care-giving role disrupting their labour market participation (EUROFAMCARE Consortium, 2006; Carers UK, 2007). Working-aged informal care-givers are less likely to be employed than their non-caring counterparts (Vlachantoni, 2010), with economic activity rates being significantly affected by the intensity of care-giving (Mooney et al., 2002; Bittman, Fast, et al., 2004; Carmichael et al., 2010). However, even care-giving responsibilities of between 10 (King and Pickard, 2013)<sup>26</sup> and 14 hours per week (Spiess and Schneider, 2002, p. 33)<sup>27</sup> are noted to have a depressing effect on the level and nature of care-givers' labour force participation. Informal care-givers may change their job or work patterns in order to manage their caring responsibilities (Glendinning, 1992; Evandrou and Glaser, 2003), including reducing their working hours or giving up work altogether (Pickard, 2007;

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<sup>26</sup> Among men and women aged 50 plus.

<sup>27</sup> Among women.

Vlachantoni, 2010; Milne et al., 2013; Principi et al., 2014). A survey conducted by Carers UK (2007) found that care-givers lost £11,000 a year on average in earnings. Moreover, in the UK 2.8 million carers combine paid employment with informal care (Yeandle and Buckner, 2007). Care-givers attempting to reconcile their work and care-giving roles are at risk of experiencing welfare loss. They report: being stressed; having less time for themselves and their families; their work performance being affected by poor concentration; and having high levels of absenteeism to deal with care-giving responsibilities including being forced to use their annual leave entitlement (Mooney et al., 2002, pp. 16–18).<sup>28</sup>

### ***Extended life-course risks***

Working-aged carers can also experience extended life-course risks which can affect their long-term financial security, the longer the duration of their caring role the more significant the impact. Two-thirds of informal care-givers in the Eurofamcare study had provided elder care for more than two years, with the average duration being five years (EUROFAMCARE Consortium, 2006, p. 118). A significant issue for care-givers taking time out of the labour market is that post-industrial employment is characterised by professional and technological skills which are subject to frequent change. Former care-givers attempting to re-enter the labour market may find that their pre-existing skills, qualifications and work experience have become obsolete (Lundsgaard, 2005; Jenson and Saint-Martin, 2006) thereby affecting their career development and requiring them to amend their career aspirations (Fry et al., 2011). Meanwhile care-givers who downgrade to less skilled work or part-time employment may find their economic status undermined not only by inferior pay but also by a lack of training opportunities affecting their career advancement (Gallie, 2002; Spiess and Schneider, 2002; EUROFAMCARE Consortium, 2006; Glendinning et al., 2009).

In addition to care-givers incurring a ‘wage penalty’ during their working lives due to their fragmented employment histories, these poverty risks can also extend into their old age in the form of a ‘pension penalty’ due to their incomplete social security and occupational pension contributions (Evandrou and Glaser, 2003; Jenson, 2004). Social insurance and occupational pension schemes in particular are not conducive for meeting the financial needs of people who have had fragmented work histories (Daly, 2000; Esping-Andersen et al., 2002; Abbott et al., 2006). Care-givers are unlikely to be able to build up an adequate pension entitlement or meet the minimum earnings level

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<sup>28</sup> Although studies have also found there to be positive effects with care-givers reporting paid work to act as a buffer against the stress of care-giving and providing important social contact (Phillips, 1994, in Mooney et al., 2002; Fry et al., 2011).

required for contributing to these schemes (Jenson and Jacobzone, 2000; Gallie, 2002). Public pension retrenchment will also place care-givers at risk of having less disposable income during their working years due to having to pay higher social security contributions, and having to work beyond retirement age, either to accrue adequate pension rights or alternatively to supplement their inadequate pension income. Informal care-givers may also face extended poverty risks into their own dependent old age if they have had to use their savings to cover the costs associated with their care-giving (Glendinning, 1992; Glendinning and McLaughlin, 1993; Carers UK, 2014a).

### ***Gender-related risks***

The gendering of care-related risks takes two forms. Firstly, women are more likely to require care provision in their old age than men due to experiencing poor health for a longer duration (Eurostat, 2011; Office for National Statistics, 2014a). Women account for approximately 72 per cent of the older people with a severe disability in the UK (Comas-Herrera, Pickard, et al., 2010), with Eurofamcare data showing women to account for 68 per cent of elderly informal care recipients (EUROFAMCARE Consortium, 2006, p. 254). These gender differences are explained by men experiencing a higher incidence of fatal illnesses such as heart disease and stroke, while women generally live longer than men and experience more disabling conditions such as cataract, hip fractures, arthritis and dementia (Mackenbach et al., 2005; Vlachantoni et al., 2011; Alzheimer's Society, 2014). Secondly, gender differences also exist in the provision of informal care. The latest Census data for England showed 58 per cent of informal carers are women (Office for National Statistics, 2013b). Other studies show that across most age groups women generally provide more care, more often than men (Mooney et al., 2002; Pickard, 2008; Del Bono et al., 2009; Glendinning et al., 2009; The NHS Information Centre, 2010a).<sup>29</sup> Moreover, the bulk of the informal care provision in England falls on people during middle age, particularly between the ages of 50 and 64, and disproportionately falls on women, with 23.5 per cent of women in this age group compared to 16.9 per cent of men providing some level of unpaid care (Breeze and Stafford, 2010; Office for National Statistics, 2014b). This ensures that immediate and extended life-course poverty risks remain significantly gendered. Women's informal care-giving responsibilities are more likely to negatively affect their employment hours and earnings, in addition, female care-givers are less likely to work than male care-givers, or if employed, are significantly more likely to work part-time (Arksey and Kemp, 2006; Office for National Statistics, 2013b). This in turn contributes to them accruing fewer

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<sup>29</sup> The exception is among the over 65 age group where men provide more informal care than women due to providing more informal care as spouses (Pickard, 2007; Del Bono et al., 2009; Vlachantoni, 2010; Breeze and Stafford, 2010; Office for National Statistics, 2013b).

savings and incurring greater pension penalties in old age (Daly, 2000; Jenson and Jacobzone, 2000; Evandrou and Glaser, 2003; Yeandle et al., 2006; Pickard, 2007; Yeandle and Buckner, 2007). These life-course poverty risks are also augmented for women because many women face additional caring responsibilities during their life course in their role as mothers caring for their children (Taylor-Gooby and Larsen, 2004; Arksey and Kemp, 2006; Millar, 2006). Together these dual caring responsibilities, which may either take place consecutively as child care gives way to informal caring for elderly parents, or simultaneously, can cause multiple disruptions to women's working lives (Attias-Donfut et al., 2005; Ben-Galim and Silim, 2013). The phenomenon of 'sandwich carers' also particularly affects women during middle-age who can find themselves caring for their elderly parents and either their dependent, or partially dependent children, on account of later child-bearing or supporting children into early adulthood due to socio-economic changes, or else caring for their grandchildren (Mooney et al., 2002; Pierret, 2006; Grundy and Henretta, 2006, p.709; Breeze and Stafford, 2010; Brown, et al., 2014). Attempting to combine work and caring roles or multiple caring roles simultaneously also has the potential to generate welfare risks, with middle aged care-givers reporting poorer health and self-rated quality of life and experiencing restrictions to social and leisure activities (Brown, et al., 2014; Office for National Statistics, 2013e).

### ***Class-based risks***

Socio-economic status can affect the likelihood of requiring and providing care. Research shows the burden of morbidity to be greater for lower socio-economic groups. SHARE data reveal that people aged over 50 in low income groups are significantly more likely to experience a stroke and have increased limitations in activities of daily living than more affluent groups (Kok et al., 2008, p. 126). Meanwhile, more deprived local authorities in England are found to have higher proportions of people providing informal care (Young et al., 2006). Other studies also show a higher incidence of informal care-givers to have no, or few, educational qualifications (Pickard, 2008; Fry et al., 2011), and to be providing more intensive levels of care. Male and female carers providing 20 hours of care or more per week are more likely to be clustered in lower level jobs, whereas people with university degrees are less likely to have very demanding caring roles (Yeandle et al., 2006). Informal care-givers in the most deprived areas of England are also found to provide 31 hours more care per week than those in the wealthiest areas (Marmot and Stafford, 2010).

Carers from lower socio-economic groups are more vulnerable to experiencing immediate and extended life-course poverty risks due to their lower earning capacity, and having less financial resources and savings at their disposal for meeting care-related costs (Graham, 1993). Additionally

the employment impacts of providing more intensive levels of care can affect their current and future earnings and pension income. Added to which wealthier families have the financial resources to purchase substitute care from formal care providers (Anttonen and Zechner, 2011). This enables them to maintain their labour market participation and can protect them from the opportunity costs of downward occupational mobility (Glendinning, 1992; Carmichael et al., 2010). Less affluent carers can also face increased welfare risks. Several studies show carers who report poor health status to have a lower socio-economic status (Pinquart and Sörensen, 2007), or to have remained in education for a shorter length of time (Tommis et al., 2009).

### ***Relational risks***

Inequalities may also form between groups of informal care-givers on account of divergent familial resources (Parker, 2000). For example, those who have little family due to having small sibling networks or being only children, may potentially be more vulnerable to experiencing poverty and welfare risks due to having fewer opportunities to share caring responsibilities and costs (Pierret, 2006; Szinovacz and Davey, 2013). Although Pickard (2007) notes that individuals who are married are more likely to provide informal care than single adults, single carers can face increased poverty risks. The provision of co-resident filial care has been found to be more common among unmarried men and women (Glaser and Grundy, 2002, pp. 333–334). Glendinning (1992) found single, co-resident care-givers to have incomes which were predominantly derived from social security benefits and well below the poverty line. Similarly, Jenson and Jacobzone (2000, p. 32) noted older, single female care-givers to have disproportionately high poverty levels.

### **3.4.3 State recognition of long-term care as a social risk**

It is evident from the proliferation of care policies implemented across post-industrial countries over the past few decades that states have increasingly begun to recognise individuals with long-term care needs and providing informal care to require some degree of social protection. The range of care policies will be discussed in detail in Chapter 4. However, in this final section the contribution that the key factors of threats, benefits and agency have had on the process of state's coming to recognise elements of long-term care as a social risk will be explored.

#### **3.4.3.1 Threats**

Population ageing is resulting in an increasing demand for care from an expanding aged population and a diminishing supply of people available to provide that care (Myles, 2002; Jenson, 2004). The

scale of this phenomenon, in relation to both the size and proportion of the population affected by the mismatch of human needs and human resources (Huber and Stephens, 2006; Morel, 2006), has been a critical factor in welfare states coming to recognise long-term care as a social risk. The 'care gap', whereby the demand for informal care for older people exceeds supply, is expected to occur in England by 2017 as old-age support ratios continue to decrease (Pickard, 2008, p. 15). Other post-industrial changes are also undermining the ability of the family to adequately manage the risks relating to long-term care. The development of advanced medical technology and health care systems which have extended life expectancy (Kitschelt and Rehm, 2006), have in turn contributed to an increasing prevalence of age-related medical conditions, such as dementia, which require long-term intensive care support (Glendinning et al., 2009).<sup>30</sup> Moreover, it is estimated that two thirds of older people diagnosed with dementia in the UK are cared for at home (Alzheimer's Society, 2014). However, families increasingly lack the human and financial capacity to manage and cover the costs of the complex care needs of older relatives unaided (Jenson, 2004). This is in part due to increased female labour market participation, the diversification of family forms and decreasing familial proximity (Daly and Rake, 2003; Bettio and Plantenga, 2004; Lundsgaard, 2005; Pavolini and Ranci, 2008). The scale of the risk of families being unable to provide adequate long-term care to their members, has placed additional pressure on welfare states to recognise long-term care as a social risk (Daly and Rake, 2003, p. 154).

Even so, running alongside the expansion of statutory intervention in the care policy field, welfare states are also simultaneously producing secondary risks through their policies. Some consider states to be engaged in the re-privatisation and redistribution of care risks which were previously socialised (Jenson, 1997, p. 187; Grootegoed and Van Dijk, 2012). Such retrenchment strategies are being undertaken to contain the perceived unsustainable public welfare costs and financial deficits caused by population ageing (Timonen, 2004; Lundsgaard, 2005; Pavolini and Ranci, 2008). These strategies include reducing state residential care provision (Pickard, 2012) in favour of cheaper community care alternatives, and promoting a greater plurality of care providers other than the state (Jenson and Jacobzone, 2000; OECD, 2005; Rummery and Fine, 2012). The residualisation of state support is also occurring through the tightening of eligibility criteria (Daly and Lewis, 1998; Vlachantoni et al., 2011, p. 2). This is contributing to wealthier people purchasing care services privately from the market, while people with lower incomes turn to their family to meet their care needs (Trydegard 2000, 2003 in Timonen, 2004), or else retain unfulfilled care needs (Grootegoed and Van Dijk, 2012). Certain types of statutory support, such as cash transfers to support informal

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<sup>30</sup> Dementia prevalence ranges from 2 per cent of 65-70 year olds to 25-30 per cent of people aged over 85 (Lobo et al. 2000, in Dewey and Prince, 2005, p. 118).

care-givers, are also viewed to be promoting the (re)-familialisation of care (Pavolini and Ranci, 2008, p. 247). Meanwhile the increased reliance on market sector care and pension provision has individualised the poverty and welfare risks of older people and their families (Myles, 2002; Mullard and Spicker 1998, in Powell and Hewitt, 2002, p. 149). Consumers are at increased risk of making unsatisfactory choices due to the complexity of market products (Burchardt 1997, in Powell and Hewitt, 2002, p. 150), and being provided with poor quality or unaffordable services (Taylor-Gooby, 2004a). Altogether these trends have led Esping-Andersen (2002, 2009) to conclude that a triple institutional failure of the market, state and family is occurring, resulting in an acute welfare deficit affecting a growing number of people.

#### **3.4.3.2 Benefits**

Williams (2012) argues for care to be regarded as a social good because it is politically and economically central to the sustainability of society. The recognition of the care of children as a social and economic good contributed to public policy interventions such as family allowances, child care and education services being implemented by states (Jenson and Saint-Martin, 2006, p. 444). Similar economic motivations cannot be said to apply to the contingency of long-term care because the productivity returns for investing in dependent older people are virtually nil since they are not engaged in productive labour (Gough 1979, in Groves and Finch, 1983, p. 162). Even so, the provision of care to dependent adults contributes to the public good and benefits society at large (Wolf, 2004, p. 110; Larkin and Milne, 2014). Jenson (2004, p. 42) notes that states started to recognise care as a social risk due to population ageing increasing the likelihood of older people having unmet care needs which poses a threat to overall societal wellbeing. Meanwhile in Nordic welfare states the acknowledgement that some citizens bore a disproportionate proportion of the cost of caring on behalf of society as a whole (Glendinning, 1992, p. 7), contributed to public policies being implemented which sought to equalise these costs across society (Lewis, 1992, p. 168).

#### **3.4.3.3 Claims-making**

The influence that claims-making has had in relation to states recognising long-term care needs and informal care-giving as social risks which require statutory protection is contested. Daly and Lewis (1998, p. 13) considered there to be little evidence to suggest that informal care-givers as a lobby group have had a determining influence on care policies in any country. A number of factors are noted to have potentially undermined claims-making in relation to informal care. Firstly, there are potential conflicts of interest between the risk-bearing members of the caring dyad (Morel, 2006, p.

229) which can have important ramifications on their capacity to mobilise around a unified goal and get long-term care onto the political agenda due to potentially wanting their needs and risks serviced by different types of policies (Barnes, 2001). Secondly, heterogeneous groups of people are engaged in informal care-giving who may experience different needs in relation to their role (Lloyd, 2006a). This fragmentation and diversity, together with the isolation of the caring role itself (Anttonen et al., 2003, p. 189), could therefore undermine the collective mobilisation of informal care-givers within political processes. Moreover, the size of the constituency affected by a particular care-related risk may not be deemed significant enough by other stakeholders to galvanise policy intervention. For example, only 6 per cent of informal care-givers caring for older relatives are of prime working-age in contrast to the much larger constituency of working parents (Eurostat 2002a, in Taylor-Gooby, 2004a, p. 10). Parental claims for policies to support the reconciliation of parental employment and child care were ultimately acknowledged by states and employers in order to serve their own activation, fiscal and economic objectives related to increasing the labour supply (Knijn and Ostner, 2002; Bonoli, 2005; Jenson and Saint-Martin, 2006; Kananen et al., 2006). However, care services and employment measures which support informal care-givers to reconcile their work and caring roles are arguably less likely to attract support from these more powerful stakeholders. Employers may even actively resist these types of policy mechanisms if they are deemed to be detrimental to business profitability and competitiveness (Crompton et al., 2003; Bonoli, 2005), with the unpredictability of long-term care provision in relation to both its intensity and duration potentially acting as a significant disincentive.

However, other academics describe England as having a strong tradition of recognising carers' independent rights and support needs (Moran et al., 2012). Moreover, the incremental gains in statutory support for informal care-givers that have been made in the UK over the past few decades are considered to be the result of successful pressure group activity undertaken by key carers' organisations, which Barnes (2001) considers effectively represent the needs of all carers. This successful claims-making activity is noted to have resulted in the implementation of the original Invalid Care Allowance (Groves and Finch, 1983, p. 161) and legislation providing informal carers with statutory rights in relation to employment support and social care, such as the right to a carer assessment (Barnes, 2001; Arksey & Kemp, 2006). Moreover, Larkin and Milne (2014) consider the carers' movement in the UK to have been politically effective and instrumental in demanding and shaping the carer strategies. Even so, Lloyd (2006a) points out that some carers' group campaigns have only been partially successful, as evidenced by the resulting policy outputs benefiting some types of informal carers but not others. The extent to which the statutory support that is available in



England adequately protects all informal care-givers from the care-related risks they face forms a key focus of my research study.

### **3.5 Conclusion**

The intention of this chapter was to make a case for long-term care, and informal care-giving in particular, being categorised as a social risk in order to fill a substantive gap within the existing social risk literature wrought by its gender blind analysis. To facilitate my ability to achieve this an analysis of the conceptualisation of social risk was undertaken in order to reveal its key characteristics and the processes through which states come to recognise particular contingencies as social risks. Existing empirical evidence has revealed that both older people with long-term care needs and their informal care-givers face poverty and welfare risks which are equivalent to those affecting risk-bearers facing other social risks. Moreover, the contingency of long-term care has also been revealed to contain particular risk characteristics which make it a unique social risk. Furthermore, empirical data have also been used to illustrate how the scale of long-term care needs and informal care-giving across the population and the inability of other institutions to adequately manage these contingencies, justify them being categorised as social risks which require statutory protection.

In this chapter post-industrial states were noted to be increasingly recognising that the care-related risks faced by members of the caring dyad require some form of state protection. The ways in which states are recognising different care-related risks through the implementation of a divergent array of policies will form the focus of the analysis in Chapter 4. Moreover, the argument made in this chapter that states may not treat all risks bearers experiencing a social risk equally and that uneven statutory protection may be provided to different groups of risk-bearers on account of how policies are designed and operationalised, will also be examined in more detail. This more detailed analysis is required in order to achieve a fuller understanding of the extent to which the post-industrial English state recognises informal care as a social risk.

## **Chapter 4: The English Care Policy Context**

### **4.1 Introduction**

Chapter 3 acknowledged that post-industrial welfare states have increasingly begun to implement policies which both recognise and seek to provide a degree of protection against the risks pertaining to long-term care needs and informal care-giving. Chapter 4 supports the construction of the empirical framework for my thesis by exploring what the care policy literature reveals about the treatment of long-term care, and informal care in particular, by states. The first half of the chapter examines: the range of care policies implemented by states; how specific types of policy mechanisms can protect caring dyad members from care-related poverty and welfare risks; and the ways in which the governance arrangements of care policies, including both institutional and inter-relational factors, can contribute to the care-related risks experiencing by risk-bearers being treated differentially. This literature review will ultimately inform my research design by setting the parameters for determining which policy mechanisms and governance arrangements will be incorporated into my research methodology.

In the second half of the chapter the focus turns to reviewing what existing studies reveal more specifically about the care policy environment in England. These studies provide key details about the complexity of the English care policy system both in relation to the diverse range of care policies available and the governance arrangements and institutional processes which affect access to statutory support. This review highlights the need for a comprehensive, empirical analysis of the English care policy environment to be undertaken in order that the extent to which the state recognises and treats informal care as a social risk can be fully realised. For it is only through undertaking a holistic and systematic analysis of the English care policy system that an understanding can be gained of how the complexity of the system manifests itself in the unevenness of statutory protection provided by the state to different types of risk-bearers and care-related risks.

### **4.2 Identifying the English care policy regime type**

The comparative care regime literature has developed a variety of typologies and taxonomies which categorise specific national contexts as a particular type of care regime. This literature helps to provide an overview of the UK care regime context. This sub-literature built upon the work of the welfare regime literature which initially focused on analysing the extent to which advanced capitalist

states rely on the welfare-producing institutions of the market and state to manage the social risks predominantly associated with the labour market. Within these analyses the UK was consistently identified as a liberal welfare state due to its reliance on market solutions and residual state protection to manage both old and new social risks (Esping-Andersen, 1990, 1999; 2002; Taylor-Gooby, 2004c). However feminist scholars criticised these studies for omitting to incorporate both the welfare producing institution of the family (Lewis, 1997, 1992; Ostner, 1993; Daly and Rake, 2003) and national care systems (Anttonen and Sipilä, 1996) into their analyses in order to reveal how states treat care-related risks. The care regime literature sought to address this gap by utilising a range of care-related dimensions to categorise a country's particular care regime type. Some studies have analysed different countries' care arrangements and their institutional welfare mix which considers the extent to which care is provided via: the state; the family; collective community support; or purchased from the market (Jenson, 2008). The results of these studies, which have each analysed data from different time periods and used different data sources (Burau et al., 2007; Lamura et al., 2008),<sup>31</sup> have consistently replicated Anttonen and Sipilä's (1996)<sup>32</sup> initial care regime classification of the UK as an (Anglo-Saxon) means-tested model. In this type of care regime the state is described as playing a significant albeit residual role in the provision of support to meet individual's long-term care needs. Public care services are targeted at citizens with low incomes using means-testing, while the market serves an important role in providing support to meet the care needs of more affluent individuals. The findings of these comparative studies are also supported by national case studies which consistently describe the UK as a neo-liberal mixed-market welfare regime (Moffatt et al., 2012) which operates a "safety-net" system (Comas-Herrera, Pickard, et al., 2010). With Bell (2010, p. 23) noting that voluntary and private sector providers supply 81 per cent of publicly funded home care in England. Meanwhile Kraus et al.'s comparative study (2010, p. 39) drew the additional conclusion that as well as the UK's care arrangements featuring moderate formal care use and high levels of private funding, there is also a heavy reliance on informal care provision.<sup>33</sup> Rummery and Fine (2012) also describe the UK to have strong political support for a 'family care first' care ideology despite there being a choice of publically funded care options. Comparative studies have also analysed the long-term care policy strategies adopted by different

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<sup>31</sup> Burau et al. used data on formal and informal home care for older people from 1990's–2000's. Lamura et al. used data from the EUROFAMCARE study (2006) relating to the informal care of older people.

<sup>32</sup> Anttonen and Sipilä analysed formal social care provision for children and older people using data from the late 1980's.

<sup>33</sup> Kraus et al. categorised the UK as falling between a 'family care model' and a 'state responsibility model' using SHARE data and primary data from 2006 relating to the provision, organization and financing of long-term care.

states to address the recognised needs of informal carers. Kautto's (2002)<sup>34</sup> and Pavolini and Ranci's (2008)<sup>35</sup> studies found most countries, including the UK, to be gradually moving away from the traditional dichotomy of either providing cash transfers with a view to promoting family care or providing care services with a view to replacing family care, towards a greater 'care mix' combining both sets of strategies. While Mestheneos and Triantafillou's (2005) study noted how the UK state recognises informal carers as a group of citizens with special needs through granting carers limited rights to cash payments.<sup>36</sup>

Although these comparative studies and typologies are helpful for providing a general national overview, they lack the analytical breadth and depth required for providing a more nuanced and detailed understanding of the complexity of a state's care policy environment. For several authors highlight that national care arrangements are complex and often contradictory (Pfau-Effinger, 2012). National care policies are noted to often lack overarching policy coherence within and across multiple policy domains (Daly and Rake, 2003, p. 68), due to diverse policy measures underpinned by different principles being used simultaneously (Burau et al., 2007; Powell and Barrientos, 2011; Bihan and Martin, 2012). Consequently Anttonen et al.'s (2003) attempt to develop a taxonomy of the social care arrangements in five countries<sup>37</sup> was aborted due to finding: universal social care provision conferring genuine citizenship rights to exist alongside selective and sharply rationed care provision; policies that replace family care being simultaneously pursued alongside those which shore up weakening patterns of obligation among families; and local and regional variations occurring in how social care is delivered and used in the same national context.

### **4.3 Scoping the English care policy environment**

The care policy literature helps to reveal the specific ways in which states recognise the care-related risks experienced by care-receivers and care-givers by providing a more detailed, although mainly descriptive, analysis of the types of statutory support mechanisms that are available across different national contexts. The literature identifies three main types of care policy provision used by states in relation to long-term care, each of which seeks to serve different social protection purposes. These include: social security and other monetary benefits which compensate people financially for

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<sup>34</sup> Kautto analysed fifteen countries in relation to their social protection programmes including pensions, health care, care services and cash transfers for care at two points in time (1990 and 1997).

<sup>35</sup> Pavolini and Ranci analysed the coverage levels of long-term care service provision and cash benefits for six European countries using data from the 1990's and 2000's.

<sup>36</sup> Analysing data from the EUROFAMCARE study.

<sup>37</sup> Japan, Finland, UK, US and Germany.

either the provision of care or the costs incurred in requiring care; employment-related measures which facilitate the reconciliation of care and employment roles; and cash benefits or services in-kind which provide support and replacement care thereby maintaining or substituting informal care provision (Daly, 2001; Daly and Rake, 2003; Bettio and Plantenga, 2004). Different types of care policies can serve different functions in relation to addressing the caring dyad's needs and risks. Several authors recognise the need to analyse the adequacy of public care policy provision in relation to how they protect individuals from poverty risks (Ungerson, 1997). They recommend considering the extent to which policy mechanisms are sufficient for meeting informal care-givers' financial requirements for a decent standard of living (Keigher and Stone, 1994) and provide sufficient compensation for the current and future economic consequences of performing informal caring work (Jenson and Jacobzone, 2000, p. 9). However, there is also a need to consider the extent to which different care policies can help to alleviate time poverty and welfare risks. My own analysis about how individual policy mechanisms can protect both members of the caring dyad from the care-related risks which they face is therefore also incorporated into this element of the literature review.

### **4.3.1 Cash transfers**

Figure 7 provides a synthesis of the different types of cash payments and fiscal measures which may be provided by states, and identifies those policy mechanisms which are found in the UK. It shows the key distinctions between each type of cash transfer including: which member of the caring dyad they are paid to; the nature of the role which the recipients subscribe to; the main policy objectives of each scheme; and the extent to which they are regulated by the state. Categorising these attributes helps to expose which member of the caring dyad states consider to be risk-bearers and which financial risks states recognise.

Figure 7: Categorising cash transfers

Cash Payment Schemes				
Recipient	Care-receiver		Informal care-giver	
Scheme type	Routed wages schemes (Ungerson, 1997)	Disability and care allowances/ benefits	Care-giver allowances paid via tax / social security system	Proper wages for care provision
UK Scheme	Direct Payments	Attendance Allowance	Carers Allowance	Not used
Role of recipient	Employer	Benefit recipient	Benefit recipient	State Employee
Objective	Employ care-giver	Cover disability/ care costs	Provide income/ wage replacement	Provide wage and employment rights
Level of regulation	Regulated	Unregulated	Unregulated	Regulated
Other financial / fiscal benefits				
Scheme Type	Tax Allowances		Social Security measures	
UK Scheme	Not used		Carers Credit Scheme Carers Allowance	

Sources of data: (Lundsgaard, 2005; Burau et al., 2007; Ungerson and Yeandle, 2007; Glendinning et al., 2009).

Each type of cash transfer has the potential to alleviate different types of poverty-related risks faced by members of the caring dyad, however the extent to which they do so in practice can vary considerably. There are two types of cash payments paid directly by the state to informal care-givers, care-giver allowances and proper wages schemes. Glendinning and McLaughlin (1993) consider that care-giver allowances, such as the UK's Carers Allowance, are underpinned by the principle of social security wage replacement. The payment is intended to acknowledge and compensate informal care-givers financially for the income from paid employment that is lost due to care-giving, rather than being perceived by the state as a wage for caring (Glendinning, 2006; Riedel and Kraus, 2011). McLaughlin and Glendinning (1994) note that this type of statutory entitlement reveals states to recognise that time spent caring presents a social-economic risk to individuals in terms of inequality, poverty and restrictions on life chances. However many authors state that the generosity level of this type of cash benefit is unlikely to permit informal care-givers' economic autonomy due to payment levels generally being 'exceptionally low' (Knijn and Kremer, 1997; Wiener 2003 p.14 in Glendinning, 2006, pp. 134–135; Lewis, 2006). These types of cash payments are therefore not guaranteed to alleviate the immediate poverty-related risks faced by care-givers.

Consequently this may contribute to augmenting working-aged carers' time poverty risks by forcing them to combine care-giving and employment in order to avoid living in financial poverty. In contrast the proper wages schemes implemented in Sweden and Finland (Lingsom, 1994), entail informal care-givers being formally employed as employees of the state, subject to proper wages and associated contractual and social security rights (Glendinning and McLaughlin, 1993; Ungerson, 1997; Glendinning, 2006). Although the wages of these informal care-givers tend to be lower than those paid to formal care workers (Sipilä and Anttonen, 1994; Glendinning, 2006; Glendinning et al., 2009), these schemes can be argued to represent an intention by states to protect care-givers from immediate and extended poverty risks through the recognition of informal care-giving as a form of work (Lingsom, 1994, p. 69).

Several types of cash payments for care-receivers also exist. Care and disability allowances, such as the UK's Attendance Allowance, are primarily intended as a form of financial compensation for care-receivers who have disability or care-related needs (Ungerson, 1997; Lundsgaard, 2005; Riedel and Kraus, 2011). They therefore have the potential to alleviate care-receivers' care-related poverty risks to some extent. Moreover, due to their unregulated nature older people can also use these disability benefits as financial 'gifts' to lubricate reciprocal systems of care within their social support networks (Ungerson, 1997; Lundsgaard, 2005; Glendinning, 2006). However, the low generosity level of these cash payments generally enable care-receivers to only offer their informal care-giver a notional symbolic payment (Ungerson, 1997) which cannot be said to offset the poverty risks they may face. In some states, such as Austria and Italy, more generous care allowances are provided which the state explicitly intends to be used as a form of routed wages, allowing care-receivers to pay their informal care-givers albeit at below market rates (Glendinning, 2006). However, the extent to which these unregulated schemes alleviate the immediate poverty risks of informal carers is partly subject to the discretion and generosity of the care-receiver. For some evidence suggests that older people in receipt of these allowances often do not pay their informal care-givers regularly or do not pay them at all (Jenson and Jacobzone, 2000).

Some states provide regulated routed wages schemes. These schemes are intended to promote user empowerment and choice (Morris, 1997; Timonen et al., 2006; Ferguson, 2007; Dickinson and Glasby, 2010) and develop the welfare mix via the marketisation of social care provision (Glendinning, 1998b; Ungerson and Yeandle, 2007; Le Grand, 2007b). In the case of the UK's direct payments scheme, the state makes a regular payment directly to the care-receiver which they must use specifically to either formally employ their own carer or pay for care and support services. The

selected care-givers enter into a formal employment contract with the care-receiver which provides them with a wage and associated social security contributions for providing care for a specified number of hours. This may protect care-givers from immediate poverty risks as well as extended poverty risks (Ungerson, 2004). However, some scholars have criticised the UK state for using direct payments to justify reducing state expenditure (Daly, 2002; Ferguson, 2007; Ungerson and Yeandle, 2007; Needham, 2011). For states often ascribe a lower monetary value to these types of cash payments than the cost of providing equivalent services, based on the assumption that care-receivers have less bureaucratic overheads (Glendinning, 2006, p. 131). Moreover Needham (2011, p. 62) notes that service users are often expected to manage their budget more frugally and effectively than the state does on their behalf. This can result in inadequate funding being provided to meet the care-receiver's assessed needs which can have time management and financial implications for their carers (Timonen et al., 2006). Furthermore, not all states permit these payments being used to employ informal care-givers (Ungerson and Yeandle, 2007, p. 192). For example, in the UK direct payments can only be used to employ informal carers if they do not live with the care-receiver (Department of Health, 2009).<sup>38</sup> However, direct payments may also be used by care-receivers to substitute their informal carer for a paid formal carer, thereby giving the informal carer a break from caring which can reduce their time poverty and welfare risks.

Other fiscal benefits which states may provide include tax allowances when purchasing care services or employing care-givers (Jenson and Jacobzone, 2000; Lundsgaard, 2005), and stand-alone social security schemes which provide national insurance credits for informal care-givers (Evers, 1994; Glendinning et al., 2009). For example, both the UK's Carers Credit scheme and Carers Allowance provide a weekly National Insurance credit which help carers accrue contributions towards their future state pension entitlements (Carers Direct, 2011b; Directgov, 2012d). This type of scheme can serve to protect care-givers against extended life-course risks such as old age poverty. Meanwhile other states also provide additional social security benefits to carers including health and disability insurance and holiday pay which can help protect against poverty and welfare risks (Pilj, 1994; Ungerson, 1995; Jenson and Jacobzone, 2000; Lundsgaard, 2005).

### **4.3.2 Care Services**

Figure 8 provides a synthesis of the types of care service provision that states may provide to support older people with long-term care needs and their informal care-givers. States may either: provide this support directly; provide the funding to commission another provider from within the

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<sup>38</sup> Unless exceptional circumstances apply and it is the only satisfactory way to meet an individual's care needs.



welfare mix to provide the support (Lamura et al., 2008); or provide funding or vouchers directly to the caring dyad for them to commission their own services (Bode et al., 2011; Häikiö and Anttonen, 2011; Directgov, 2012b).<sup>39</sup> The provision of care services serves to reveal how states recognise the need to protect both members of the caring dyad against the risk of welfare loss and, in certain cases, the risk of poverty.

**Figure 8: Categorising services in-kind**

Service category	Types of services
<b>Support for care-receiver or Support for informal care-giver via care-receiver</b>	<b>Home care:</b> domiciliary care services to provide support with personal care and domestic care tasks
	<b>Community-based support services:</b> e.g. day care, meal services, laundry services, transport services
	<b>Respite care:</b> temporary admission into residential care to relieve family care-giver; in home sitting services
	<b>Residential care:</b> permanent admission to a residential or nursing home
	<b>Equipment, aids and adaptations</b>
	<b>Information and communication technology (ICT):</b> community alarms, telecare, <sup>1</sup> online support and advice services
<b>Support for informal care-giver in their own right</b>	<b>Education and training:</b> on providing care, manual handling, protecting health etc.
	<b>Advice and information:</b> carers' centres, online information, telephone help-lines
	<b>Emotional support services:</b> counselling, support groups, befriending schemes, advocacy
	<b>Care Services:</b> to support care-giver work load, carer personal budgets
	<b>Information and communication technology (ICT):</b> online discussion forums, websites, internet-based training courses

*Sources of data:* (Evers, 1994; Pilj, 1994; Daly, 2001; Daly and Rake, 2003; Wiener, 2003; Mestheneos and Triantafillou, 2005; Lundsgaard, 2005; EUROFAMCARE Consortium, 2006; Lamura et al., 2008; Glendinning et al., 2009; Yeandle and Fry, 2010).

*Note:*

<sup>1</sup> Telecare describes a range of technology which can monitor a person's health, wellbeing and safety through the use of sensors in their home which notify a call centre operative to take action if something unusual is detected (Carers Direct, 2011f).

The services provided directly to care-receivers can perform two functions. Firstly, they can enable dependent older people to continue living safely within the community thereby protecting them

<sup>39</sup> The latter refers to the routed wages schemes described in the cash transfer section.

from welfare-related risks. Secondly, the provision of replacement care services such as domiciliary care and respite care can support informal care-givers to continue caring or stop caring by supplementing or substituting for them in their care-giving role (Daly, 2001; Glendinning, 2006, p. 131). By providing additional support or a break from their care-giving responsibilities on either a temporary or permanent basis, carers can be protected against the welfare and time poverty risks which they face (Daly and Rake, 2003; Glendinning et al., 2009). Furthermore replacement care services can also protect working-aged informal care-givers against poverty risks if the service provision substitutes them for a long enough duration that they are able to access the labour market (Orloff, 2002; Lundsgaard, 2005). The generosity levels of service provision is therefore of critical importance for protecting care-givers against care-related risks. If the level of service provision is not adequate in terms of both the service frequency and duration, it will not provide care-givers with enough time to either engage in paid employment or to have an adequate rest from care-giving.

The care services which are provided directly to informal care-givers can also serve to protect both members of the caring dyad from welfare loss. For example, care-givers may be provided with advice and information about the medical conditions experienced by the person they care for, or training about practical care-giving techniques (Lundsgaard, 2005; Burau et al., 2007; European Commission, 2008). Moreover, they may be provided with access to counselling or a support group which supports them to manage the emotional demands and isolation of their care-giving role (Lundsgaard, 2005, p. 31). They may also be provided with a direct payment or services in their own right to enable them to have a break from their caring responsibilities and to access leisure activities. This support may be provided with a view to promoting care-givers' wellbeing and protecting them from the risk of injury or emotional distress (Glendinning et al., 2009, p. 19). However, arguably, this objective may only be of intermediate concern to the state rather than being an end in itself (Twigg, 1989). For the focus of this type of state intervention may ultimately be to promote the quality of the care provided to the care-receiver and sustain the carer in their care-giving role, thereby reducing the need for more costly statutory support interventions.

### **4.3.3 Employment-related measures**

Figure 9 provides a synthesis of the types of employment support mechanisms that may be provided to assist carers of working age to reconcile their work and caring roles.

**Figure 9: Categorising employment support measures**

Category of Support	Type of employment support mechanisms
<p style="text-align: center;"><b>Care leaves and associated provisions</b></p>	<p><b>Care leaves:</b>                      Time off for emergencies (UK Statute)                      Paid or unpaid employment leave (short term)                      Extended leave/ career breaks for family reasons                      Annual leave for family reasons</p>
	<p><b>Income protection:</b>                      Income compensation for lost earnings                      Other financial protection e.g. National Insurance contributions</p>
<p style="text-align: center;"><b>Flexible working arrangements</b></p>	<p><b>Flexible work arrangements:</b> (UK Statute)                      Flexible work arrangements (hours, place of work, contract type)                      Flexi schedules                      Part-time work or reduction of working time                      Home working                      Time Off in Lieu (TOIL)</p>
<p style="text-align: center;"><b>Other types of employment support</b></p>	<p><b>Legislative protection:</b>                      Employment protection legislation                      Re-employment guarantee                      Protection against discrimination due to caring role (UK Statute)</p>
	<p><b>Information and advice:</b> on employment rights and policies</p> <p><b>Training:</b>                      Access to training/re-training to support care-givers to (re-)enter the labour market                      Courses to build confidence and support with application and interview preparation                      Accreditation courses for full-time carers</p>

*Sources of data:* (Glendinning et al., 2009; Yeandle and Buckner, 2007; Yeandle et al., 2007; Bettio and Plantenga, 2004; Daly and Rake, 2003; Mooney et al., 2002; Phillips et al., 2002; Evers, 1994; Pilj, 1994).

The two key employment support measures - care leaves and flexible working arrangements - have the potential to protect informal care-givers in two ways. They can guard against the risk of welfare loss by supporting carers to reconcile their work and caring roles thereby lessening the risk of time poverty and associated stress-related problems. They can also reduce the risk of poverty by either permitting carers to continue to participate in the labour market or temporarily decommodifying them during periods spent caring. However, the extent to which they achieve either objective varies significantly across countries. For it depends on how much time off is permitted to undertake care, the circumstances under which care leave is agreed (planned or emergency care situations), and the extent to which financial compensation is provided. Only paid care leave schemes, such as those

found in Sweden and Ireland,<sup>40</sup> which transform informal care into a form of paid work, can protect against immediate poverty risks (Jenson, 1997; Lundsgaard, 2005; Glendinning, 2006). Unpaid care leave on the other hand only provides protection from extended poverty risks in a tenuous way by protecting care-givers' longer-term job security and links to the labour market. Moreover, countries can vary significantly as to whether these support mechanisms are guaranteed as social rights by the state within national legislation or whether they are implemented by individual employer organisations as voluntary agreements with their employees. This can have implications for the consistency of protection provided to different care-givers within the same national context.

The care policy literature helps to reveal that states do recognise the care-related risks associated with informal care as social risks as evidenced through the array of care policy mechanisms which they implement. However this literature, which primarily undertakes a macro level comparative analysis of care policies, provides a mainly descriptive account of these statutory interventions and does not empirically analyse how these mechanisms are implemented in practice within national contexts. The finer detail of the governance arrangements underpinning individual care policy mechanisms and whether these mechanisms recognise and offer equal levels of statutory protection to all risk-bearers, is therefore not explored. A more thorough examination of the way in which institutional processes and inter-personal factors can impact on the extent to which the care-related risks experienced by different types of care-receivers and care-givers are recognised and subsequently protected by statutory mechanisms is therefore required. There is also a need to consider the overarching range and combination of policy mechanisms available within each national context and policy domain. This is because different types of informal care-givers may require different configurations of policy mechanisms to meet their needs depending on their characteristics and the nature of their care-giving role. For example, replacement care services may be more essential to the quality of life of older care-givers (Glendinning, 1998a,b), whereas working-aged care-givers may require paid care leaves or flexible working so that they themselves can provide the care required.

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<sup>40</sup> Both countries have collectively funded income replacement benefits for employees who take temporary leave from work to care for critically or terminally ill relatives (Glendinning, 2006).

## **4.4 Analysing the governance arrangements of care policy mechanisms in England**

In order to explore the extent to which the English state both recognises and seeks to protect different groups of care-receivers and care-givers from care-related risks through its care policy mechanisms it is necessary to consider the governance arrangements which can influence the construction and implementation of welfare policies. The existing literature highlights a number of key governance dimensions that will be taken into account in my research design. These include institutional factors such as how states use entitlement principles and eligibility criteria to categorise which groups of risk-bearers are eligible or excluded from accessing statutory protection; and the extent to which the decentralisation of care policy implementation can contribute to territorial variations in statutory support outputs. The ways in which policy approaches such as personalisation can affect the consistency of entitlements is also examined. Inter-personal factors are also considered, including how the discretionary decision-making of practitioners and the personal attributes of individuals can contribute to inequalities occurring in the level of statutory protection provided.

### **4.4.1 Institutional factors affecting access to statutory protection**

#### **4.4.1.1 Principles of entitlement and eligibility criteria**

The design of policy mechanisms determines which risk-bearers the state recognises and can influence the level of statutory protection they are deemed to require. Fraser (1994, pp. 614–615) considered how care policies could be underpinned by a range of distributive principles including need, desert and citizenship. Each set of principles provides an indication of the value attributed by the state to the activity of care-giving and the extent to which the state attempts to protect the risk-bearers' wellbeing. For example, where states provide statutory support according to the principle of need, as in the case of social assistance schemes, only the poorest individuals are targeted using means-testing and the statutory support provided is only intended to prevent absolute poverty risks accruing to the risk-bearers (Österle, 2001, pp. 102–103). Fraser (1994) argued that care-giver allowances provided under these conditions prevent care-giving as an activity being awarded equal value and parity to breadwinning. In contrast care-giver allowances provided according to the principle of desert provide more generous benefits which protect care-givers from large reductions in their economic living standards (Österle, 2001). This type of scheme reveals the state to recognise and compensate care-givers for contributing towards socially necessary service or work (Fraser, 1994). Meanwhile where the universalist principle of citizenship is applied more generous state

support is provided with a view to reducing income inequality by redistributing resources horizontally between those individuals affected by long-term care needs and those unaffected (Österle, 2001). This categorisation tool is useful for determining the value attributed by states to care-giving through the design of their care policies. However, it is only by analysing the specific eligibility criteria applied to policy mechanisms that it is possible to determine the extent to which the state recognises all types of care activity and care-givers to require statutory protection.

States use eligibility criteria to define the categories of risk-bearers who they consider to be entitled to gain access to state protection against recognised social risks. Analysing the eligibility criteria used within care policies can therefore reveal the extent to which the state recognises and seeks to protect different groups of care-givers and older people from the care-related risks they face. According to Österle (2001, p. 139) the main criteria which determine the allocation of state resources are need, status, economic and time-related principles.

Need is commonly used within the eligibility criteria of long-term care policies in order to differentiate between which care-givers and care-receivers can access statutory support. Moreover, states may apply different dimensions of need to determining access to state support. For example, statutory support targeted at care-receivers tends to take into account the care-receiver's disability and health-related circumstances or their level of inability to carry out certain tasks (Österle, 2001). Meanwhile the access of informal care-givers to state benefits and services often requires the health needs of the care-receiver as well as the amount of care provided by the care-giver, measured as time, to be taken into account (Carers Direct, 2011c). States may apply additional time-related eligibility criteria, as in the case of the Attendance Allowance scheme whereby a claimant needs to have experienced a health problem for six months before a claim can be agreed (Carers Direct, 2012c). States may also determine eligibility according to the types of care tasks which they are prepared to provide support with (Burau et al., 2007). This often involves eligibility criteria distinguishing between a higher dependency tier consisting of medical assistance and personal care and a lower dependency tier consisting of domestic support (Christopherson 1997, in Daly and Rake, 2003, p. 57). Evidence suggests that due to financial constraints states are increasingly excluding domestic tasks and social activities from the list of essential care tasks which they are willing to fund (Keigher and Stone, 1994; Österle, 2001; Ellis and Davis, 2001; Häikiö and Anttonen, 2011). This is resulting in the 'intensification' of statutory care provision (Vlachantoni et al., 2011, p. 3), which is increasingly being focused on meeting the personal care needs of the most vulnerable older people (Ellis and Davis, 2001; Kemshall, 2001; Glendinning, 2012). The boundary setting undertaken by

states in relation to whether their needs-testing is more or less generous (Vabo and Burau, 2011) can therefore impact significantly on the extent to which different types of care-givers are protected against the risk of welfare loss and poverty. The literature identifies those groups who are more likely to be excluded from statutory protection to include those care relationships where older people have lower levels of dependency, and require support with domestic tasks, or care of a short-term duration (Rauch, 2007; Vlachantoni et al., 2011; Glendinning, 2012).

Economic principles including income levels, assets, and labour market participation levels are also commonly used by states in their eligibility criteria for determining access to cash benefits and services (Österle, 2001). For example, earnings-related measures or means-tested measures may be implemented so that only low income care-givers falling beneath a minimum income level will be considered eligible to receive state support (Parker, 2000). States may also use a care-giver's employment status to determine eligibility, with care-givers who continue to work potentially being excluded from receiving benefits, or receiving less generous benefits. If statutory support in the guise of care services is provided, economic principles may be applied to assessing the financial circumstances of members of the caring dyad in order to determine how much in the way of user fees they can contribute towards the cost of their care. This can serve as an additional means to ration services, with higher fees being more likely to restrict access to state support (Lundsgaard, 2005; Kildal and Kuhnle 2005, p.15 in Vabo and Burau, 2011).

States may use multiple configurations of characteristics within the eligibility criteria of a single policy mechanism. This can mean that the risks experienced by informal care-givers providing a similar level of care may be treated in divergent ways according to whether their other characteristics are also categorised as permitting access to statutory support. The application of status-related eligibility principles, including age, civil status, family status and occupation to policy mechanisms (Österle, 2001), can contribute to the inconsistent treatment of risk-bearers. For example, as previously mentioned the use of direct payments in the UK is affected by the relational status and living arrangements of the members of the caring dyad (Glendinning, 2006; Directgov, 2012c). Moreover, the original Invalid Care Allowance scheme contained both age-related and marital status criteria which excluded informal care-givers over the age of 65 and married female carers from accessing this financial support regardless of how much care they were providing (Walker and Walker, 1991; Glendinning and McLaughlin, 1993).

The literature usefully describes how states apply different characteristics to their eligibility criteria to determine access to statutory support (for example, Bihan and Martin, 2012). However, an in-depth empirical analysis is required of how the specific configurations of characteristics used by states give rise to unevenness in the statutory protection provided across risk-bearers, which can leave some sub-groups less well protected. Further exploration is also needed as to the level of parity that exists across the eligibility criteria of different statutory support mechanisms, and the extent to which an individual risk-bearer may be subjected to differential access to statutory protection across policy domains and mechanisms. For as Bell (2010, p. 7) acknowledges the UK cash benefit and social care systems 'do not serve identical groups of clients, largely due to differences in their assessment procedures'. A more nuanced analysis of the ways states demonstrate their recognition of care-related risks and risk-bearers through the construction of their eligibility criteria is therefore required.

#### **4.4.1.2 Decentralised governance structures affecting consistency of statutory protection**

The level of statutory protection that can be accessed by risk-bearers can also be affected by whether welfare entitlements are based on national or local citizenship. The issue of territorial inequality in welfare provision within nation states has been subject to considerable theoretical exploration within the social policy and political science literature (Powell and Boyne, 2001; Powell et al., 2001; Segall, 2007; Williams and Mooney, 2008; Chaney, 2013). Some argue that a territorial justice principle should be applied by states in order to uphold citizens having equal social rights in relation to welfare provision at a national level. This would ensure that any individuals in identical need receive an identical statutory response<sup>41</sup> regardless of where they live in the country (Powell and Boyne, 2001, p. 184; Kay, 2005). However, in welfare systems where the implementation of care policies are decentralised to the level of municipalities, geographical inequalities in the rights and entitlements of risk-bearers living in different localities can often emerge (Powell and Boyne, 2001; EUROFAMCARE Consortium, 2006; Segall, 2007; Williams and Mooney, 2008; Vabo and Burau, 2011). This issue is of relevance to the English care policy context, for although the cash benefits system promotes territorial equity by providing uniform financial support to older people and their carers throughout the UK (Bell, 2010), adult social care is a key responsibility of local authorities. National legislation exists which confers statutory rights on eligible individuals in relation to key aspects of care support. However, decentralised governance structures enable local authorities to retain certain levels of autonomy over how they service different levels of needs amongst their populations (Powell and Boyne, 2001; Bell, 2010). For example, they can apply discretion to

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<sup>41</sup> Which may be in relation to equality of expenditure, provision, access, use and outcome.



determining who can access statutory support in their area, and the level of resources they allocate in relation to the range and quality of services that they provide.<sup>42</sup> Consequently the care services policy domain has been described as being subject to a postcode lottery (Commission for Social Care Inspection, 2008; Bell, 2010; Commission on Funding of Care and Support, 2011; Brand et al., 2012; Lymbery, 2012), which permits the existence of asymmetric social rights across the country (Kay, 2005).

Successive governments have attempted to promote greater equity across local authority care policies and provision through issuing guidance documents on eligibility thresholds (Department of Health, 2003a, 2010a) and charging policies (Department of Health, 2003b, 2010b, 2013a). However, geographical variations continue to persist in relation to the statutory offer made to local people (Department of Health, 2013b). Inconsistencies are found in: the level and type of social care provided, including the provision of direct payments (Comas-Herrera, Wittenberg, et al., 2010; Glendinning, 2012); the financial charges applied (Bell, 2010; Commission on Funding of Care and Support, 2011); and the needs which are deemed to be 'eligible' (Fernandez and Snell, 2012; Department of Health, 2013b). A number of factors are noted to undermine greater consistency in statutory support outcomes being achieved. Local authority budgets are being placed under increasing pressure on account of: population ageing (Vlachantoni et al., 2011); the chronic underfunding of adult social care (Commission for Social Care Inspection, 2008; Glendinning, 2012); and more recent austerity measures (Lymbery, 2012). Furthermore, the Coalition Government's own localism agenda is committed '.....to shifting power away from Whitehall to those who know what will work best in their local communities' (Department of Health, 2010c, p. 35). Advocates of localism accept geographical variations as 'evidence of the success of responsiveness to the local population', while national uniformity in welfare provision is construed as a potential failure of local democracy (Powell and Boyne, 2001, p. 186). The extent to which central government should 'continually interven[e] to restrict or direct the choices which local authorities make' (O'Higgins 1987 in Powell and Boyne, 2001, p. 185), in order to uphold territorial equity is therefore subject to dispute (Chaney, 2013).

The existing literature has tended to analyse territorial inequalities in the UK either from a theoretical perspective or else has focused on analysing a specific element of the social care system, such as eligibility policies (Fernandez and Snell, 2012). A more systematic empirical analysis is therefore required in order to reveal how territorial variations can emerge across multiple stages of

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<sup>42</sup> For example, Glendinning (2012, p. 293) reports that the proportion of local authority expenditure that is spent on adult social care, ranges from 21 to 54 per cent across councils.

the institutional processes through which individuals gain access to statutory support. The extent to which the members of the caring dyad are consequently subjected to inconsistent statutory protection in the care services and employment support domains on account of where they live and work also requires further consideration.

#### **4.4.1.3 Implications of personalisation for statutory support outputs**

Another area of potential inequality that requires exploration relates to the individualising effects of personalisation. Personalisation has been promoted by both New Labour Governments (Department of Health, 2005, 2006; HM Government, 2007) and the Coalition Government (Department of Health, 2010a,d; HM Government, 2012a) as a key policy for transforming and modernising adult social care in England. It is central to fulfilling key government objectives including: the marketisation of social care; and furthering the government's localism and consumerism agenda which seeks to transfer power from professionals to individual social care users and their carers (Department of Health, 2010c, p. 3; Dickinson and Glasby, 2010). The two key components of personalisation - self-directed assessment and self-directed support via personal budgets (Department of Health, 2010d)<sup>43</sup> - involve service users and carers determining, commissioning and managing their own tailored support (HM Government, 2007; Department of Health, 2008, p. 67). This way of working is deemed to: empower individuals to become active partners within the adult social care system (Morris, 1997; Ferguson, 2007; Dickinson and Glasby, 2010); and be more sensitive to meeting the needs of care relationships by enabling carers and care-receivers to co-produce their own mutually agreed solutions (Department of Health, 2008, p. 62, 2010c, p. 21). The benefits and disadvantages of this way of working for different groups of service users has been explored within the literature (Moran et al., 2013, 2012; Netten et al., 2012; Needham, 2011; Glendinning et al., 2008; Ferguson, 2007). Older people have been found to experience the most disadvantages: reporting lower psychological wellbeing when using direct payments (Netten et al., 2012; Moran et al., 2013); and Lloyd (2010) notes how personalisation is inattentive to the needs of more vulnerable older people experiencing frailty during the 4<sup>th</sup> age. The potential for personalisation to undermine the equity of social rights and statutory protection across individual risk-bearers in the care services and Job Centre Plus domains due to its individualising effects also requires further consideration. Foster et al. (2006) recognise that service user

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<sup>43</sup> A personal budget is an individual allocation of statutory funding which can be managed in the following ways. Either the care-receiver can ask the local authority to manage a non-cash personal budget on their behalf using it to pay for their chosen services, or they themselves or someone acting as their agent can receive a cash personal budget (direct payment) with which they purchase their own care and support services, or else they can have a combination of the two.

expectations and entitlements within a personalised model of social care requires an open public debate if equity is to be valued alongside enhanced choice. Moreover, Lipsky (1980, p. xii) has previously acknowledged the dilemma of how to ensure all citizens are treated alike in their claim on government while at the same time being responsive to the individual case.

#### **4.4.2 Inter-personal factors affecting access to statutory protection**

##### **4.4.2.1 The influence of practitioner discretion on statutory support outputs**

Barnes (2012, p. 150) states that there is a need to look at what practitioners do as well as what policy says when analysing care policies. There is an extensive literature about how welfare practitioners can affect the statutory entitlements of individuals. Lipsky's (1980) seminal work helped to reveal how 'street level' bureaucrats employ significant levels of discretion in determining who can access statutory provision. This is because policy ambiguity permits interpretation of the statutory guidelines and organisational procedures and a chronic lack of resources requires practitioners to ration access to statutory support. Practitioners therefore have the ability to distort state policy intentions through how they operationalise policies in practice. Recent empirical studies conducted within the UK context have shown that the discretionary decision-making of front line practitioners continues to significantly influence the overarching statutory support outcomes of adult social care users at different stages of the institutional process (Ellis, 2007, 2011; Evans, 2011). For example, Foster et al. (2006) revealed how practitioners can exert extensive control during the assessment process by determining the kinds of topics to be explored based on their own interpretation and assumptions about the service user's situation. Meanwhile other studies have found practitioners' decision-making about individual's eligibility bandings to be affected by their own subjective interpretations (Evans, 2011; Fernandez and Snell, 2012, p. 21).

Some studies have also revealed how practitioners in the care services domain and managers in employer organisations play an instrumental role in gate-keeping access to statutory support (Yeandle et al., 2006). Factors such as the sympathetic nature of personnel or their level of awareness about the existence of particular policy mechanisms can affect the take up of support (Mooney et al., 2002; Phillips et al., 2002; Timonen, 2004; Yeandle and Buckner, 2007; Ellis, 2007). Social work practitioners were also found to actively restrict access to statutory support: by suggesting individuals seek help privately or by securing the support of informal carers prior to discussing the statutory support that is available (Ellis, 2011). They also excluded service users from accessing personal budgets on account of paternalistic attitudes to risk and concerns about the

bureaucratic complexity entailed in implementing and managing them (Ellis, 2007, 2011; Powell, 2012; Moran et al., 2013). Meanwhile, other practitioners were found to challenge the 'gate-keeping' of statutory resources and instead advocate for service users' choices (Clapton and Kendall, 2002; Foster et al., 2006; Lamura et al., 2008; Carey and Foster, 2011). For example, practitioners in local authorities with higher eligibility thresholds were found to 'up-rate client needs ratings' (Fernandez and Snell, 2012, p. 21) and 'ben(d) the rules' to ensure people got the help they need (Commission for Social Care Inspection, 2008, p. 34).

Further empirical exploration is needed of the impact that practitioner decision-making can have on care-givers' statutory entitlements across policy domains and at the different stages of each institutional process. For although the literature acknowledges that practitioner discretion is less likely to impact on cash benefit outcomes (Ellis, 2011), the impact of practitioner and manager decision-making on the statutory support outcomes of individuals in relation to employment support also requires consideration.

#### **4.4.2.2 Negotiation processes determining access to statutory support**

The literature recognises that access to statutory support is not solely determined by street level bureaucrats but is affected by the negotiations taking place between different sets of actors. However, existing studies have tended to analyse a specific set of negotiations in isolation rather than considering the chains of negotiations taking place at different junctures of institutional processes and how these can cumulatively facilitate or undermine the caring dyad accessing statutory protection. Consequently some scholars have focused on how the decision-making of the caring dyad in relation to accessing external support can be affected by conflicts of interest between them (Twigg, 1989, 1992; Twigg and Atkin, 1994). Care-receivers may undermine care-givers having a break from caring by refusing to accept alternative statutory support or adopt lifestyle changes (Mooney et al., 2002; Leira and Saraceno, 2002; Glendinning, 2008, p. 464). Meanwhile informal carers can affect the service delivery choices available to the care-receiver. For some informal care-givers have not wanted to support care-receivers to manage their personal budgets due to being either too busy to take on this additional commitment, or in the case of older carers in particular, finding this responsibility too stressful (Department of Health, 2010c; Moran et al., 2012).

Other studies have explored the negotiations taking place between front line practitioners and service users during the assessment process (Foster et al., 2006), finding them characterised by inter-personal struggles on account of power dynamics (Lipsky, 1980, p. xiii; Barnes, 2012).

Negotiations between managers and front line practitioners, which are noted to be critical to determining individual's statutory outcomes, have also been explored. The interactions between these actors have the potential to be antagonistic and conflictual (Lipsky, 1980), particularly in the care services domain where managerialism has augmented the role of managers regulating front line practitioner's discretion (Ellis, 2011; Evans, 2010, 2011). Each set of actors may use a variety of strategies as they seek to assert and resist top down control respectively (Lipsky, 1980), with senior managers focusing on cost cutting and meeting performance targets (Evans, 2010, 2011). Meanwhile social work practitioners were found to adopt both 'positive and negative deviant practices' as they attempt to subvert agency objectives or procedures. For example, 'bending the rules' in order to overcome organisational or legal restraints that restrict the practitioner's capacity to 'get the job done', such as exaggerating needs within assessments or 'panel' applications for support services (Carey and Foster, 2011, p. 587). However, other studies have found some social services managers to adopt a more supportive approach towards practitioners in accordance with their own professional background and values (Evans, 2010, 2011), and greater convergence to exist between the interests of professionals and managers in post-managerialist welfare systems (Ellis, 2011).

Each set of negotiations can entail significant levels of emotional labour on the part of those actors involved. Jones (2013) has highlighted the importance of understanding the power of emotion in policy and the need to consider policy at the micro level of personal interactions and emotional decision-making within government agencies alongside how institutions operate at a macro level. Barnes (2012) has also specified the importance of understanding the impact that the emotional dimensions of the care relationship can have on the caring dyad's decision-making and the emotional engagement of professionals within negotiation processes. The impact that interpersonal relations within institutional negotiation processes can have on statutory support outputs therefore needs further consideration.

#### **4.4.2.3 Individual's characteristics affecting access to statutory support**

The literature acknowledges that an individual's own characteristics, skills and personality can also affect their ability to negotiate access to the statutory support and rights that are available, thereby contributing to unequal statutory support outcomes. The existing institutional barriers which are recognised to affect access to statutory support, such as the complex design of administrative systems and bureaucratic procedures; the length of waiting lists; stigmatisation; and the lack of information, understanding and awareness about the support available, could be mitigated or

compounded by an individual's personal, social, political and economic capacities and attributes (Österle, 2001; Mooney et al., 2002; Ellis, 2007; Lamura et al., 2008; Fry et al., 2011; Powell, 2012; Moffatt et al., 2012). Häikiö and Anttonen (2011, p. 193) found that care-givers who had information, contacts, and skills in utilising administrative and political power were more aware of, and more able to articulate, their rights during statutory negotiations. Consequently they could encounter different rules of access to those who lacked these inter-personal resources. An individual's knowledge and insight about their own circumstances and the range of services and support available as well as their interpersonal skills in dealing with professionals was also found to affect the equity of welfare outcomes across older people and their families (Glendinning, 2008).

The increasing importance of personalisation and consumerism in the UK social care context has generated further consideration of this issue. Le Grand (2007a,b) deemed welfare provision models which rely on user choice to be more equitable in their distribution than more paternalistic service model alternatives. However, others have challenged this, noting that being a consumer relies on 'voice' to express needs and preferences in the co-production of service choices and to negotiate contracts. Consequently consumerist approaches may serve certain groups better than others which can undermine equitable outcomes (Clarke, 2006; Ellis, 2007). For an individual's physical and cognitive impairments (Ellis, 2007; Lymbery, 2010), their degree of literacy, confidence and competence (Glendinning, 1998a), and their age (Moffatt et al., 2012) can each contribute to individuals being unprepared or unable to engage in the different mode of behaviour required by consumer-led approaches to care. Consequently it is the more educated and articulate middle classes who are advantaged within this type of system (Ellis, 2007; Ferguson, 2007).

#### **4.5 Analysing the treatment of informal carers by the state**

In this final section I review what has specifically been discussed in the academic literature and key government policies about the treatment of informal care-givers and informal care by the English state. Both sets of literature recognise the complexity of informal care-givers' needs and the English care policy system. The national carer strategies implemented by the New Labour (Department of Health, 1999, 2008) and the Coalition Governments (Department of Health, 2010c) recognise informal carers to face a range of care-related risks including: poverty risks caused by caring contributing to lower incomes and a lack of pension contributions (Department of Health, 1999, p. 25, 2008, p. 3; 5; 83); health risks caused by caring placing carers under physical and mental stress, placing them at risk of injury and causing them to ignore personal health needs due to time restrictions (Department of Health, 2008, p. 102, 2010c, p. 26); and time poverty risks associated

with attempting to balance work, care and family responsibilities (Department of Health, 1999, 2008, p. 5; 6; 70, 2010c, p. 13). Moreover, each strategy recognises the state to have a key, although not the sole responsibility, to support and protect carers against these risks.<sup>44</sup> The carer strategies also acknowledge that access to the statutory support that is available for both members of the caring dyad can be undermined by a variety of factors. These include: the adult social care legal framework being 'complex and fragmented'; the assessment processes for both carers and care-receivers being slow, unresponsive and overly bureaucratic (Department of Health, 2010c, p. 20); and significant variations existing in the quality and availability of the support offered across the country (Department of Health, 1999, p. 58, 2008, p. 6; 40). Meanwhile other government commissioned reports have also noted deficiencies with the design and function of Carers Allowance for different groups of carers and inconsistencies in the employment support provided to carers by Jobcentre Plus (National Audit Office, 2009; Fry et al., 2011).

The academic literature and government commissioned reports which have analysed the treatment of informal carers by the English state reveal how different government policies and institutional processes treat informal care-givers and their care-related risks inconsistently. Twigg (1989, 1992; 1994) devised a typology based on four ideal care-giver types which is helpful for identifying and categorising this inconsistent statutory treatment. Twigg's 'superseded care-giver model' sees the state seeking to maximise the independence of the care-receiver through statutory interventions which replace the informal care-giver with formal care services. Arguably, this model could be actualised through the personalisation approach which provides care-receivers with choice and control over how their care needs are met. This could enable individuals to reduce their reliance on informal care arrangements should they so wish and replace them with alternative sources of support. Previously this care-giver model was more commonly associated with the empowerment of younger adults with disabilities in relation to their parental carers (Twigg, 1992, p. 64) rather than older people and their informal carers. However, Pickard (2001) related this specific care-giver model to the 'carer blind' approach advocated by the Royal Commission's report on Long Term Care in 1999. The Commission's report had challenged the way in which the presence of a carer often affects the level of statutory support provided to the care-receiver and instead argued that statutory services should be provided to alleviate the burden of care from informal carers and if necessary

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<sup>44</sup> 'Caring is personal, its individual, but it is social too and the government can help in its own way' (Department of Health, 1999, p. 3); there needs to be a 'balance of responsibility' between 'the family, individual, wider society and relationship between them and the state' (Department of Health, 2008, pp. 31–33); 'government should reciprocate the support carers show with measures that ease the responsibility of caring' (Department of Health, 2010c, p. 3).

replace them entirely. Despite this recommendation subsequent studies have provided empirical examples of how the state's treatment of informal carers resembles Twigg's 'care-givers as resources model', in which the state focuses on the needs of the care-receiver while the needs of the informal care-giver remain ignored. According to this model, statutory services are provided only as a last resort in response to the deficiencies of the care network so as to avoid undermining family care responsibilities. For example, the Commission for Social Care Inspection (2008, p. 37) found practitioners making inappropriate assumptions about the willingness of carers to provide support to the care-receiver, leading to under-estimations of their level of need and risk. Meanwhile, Fernandez and Snell (2012) found that care-receivers with no informal carers were often assigned a higher eligibility banding by practitioners. Furthermore, Moran et al. (2012) found the resource allocation systems used to determine the size of a service user's personal budget typically deducted points, and therefore money, from those service users who had support from informal carers.

The 'Dilnot Report' on Fairer Care Funding, meanwhile, advocated for a 'carer sighted' adult social care system in which 'the contribution of carers is taken into account when deciding on the appropriate pack of support' (Commission on Funding of Care and Support, 2011, p. 52). According to Twigg the explicit acknowledgement of the carer's contribution can be undertaken for two distinctive reasons. In the 'care-givers as co-clients model' the state's focus is on promoting the carer's wellbeing by relieving carer strain through the provision of substitute care services to the care-receiver.<sup>45</sup> This approach is according to Pickard (2001) reflected in the initial, and I would add subsequent, carer strategies which focus on the importance of providing respite breaks to carers. Moreover, various policies recognise that carers should be supported to have a life outside caring by having their work, education, training and leisure aspirations taken into account during a carer assessment (HM Government, 2004; Department of Health, 2010c, 2008); and the legislation permits local authorities to provide carers with their own support services (HM Government, 2000). Meanwhile Twigg's 'care-givers as co-workers model' sees the state recognise the carer's needs for the instrumental purpose of ensuring the continuation of their care-giving role and upholding the provision of good quality care to the care-receiver. This approach is also reflected in the carer strategies which identify that the need to support carers to stay mentally and physically well through the provision of carer breaks is necessary to prolong their ability to continue caring and reduce the risk of potentially abusive situations developing within care relationships (Department of Health, 2008, p. 108). Other policy mechanisms such as care-giver allowances also reflect this model. The

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<sup>45</sup> Although Twigg (1989) noted how care-givers treated in accordance with this model do not have equal client status to the care-receiver and remain at best secondary clients.



application of Twigg's typology to the English state's treatment of informal carers highlights how different elements of the care policy system may treat informal carers differentially. Twigg also considered how the state may treat different types of informal care-givers differentially. She postulated that older spousal care-givers and stressed care-givers were more likely to be treated by the state as co-clients, while younger, fitter spouses were more likely to be treated as co-workers or resources. A more systematic and nuanced empirical analysis of the treatment of informal carers by care policy mechanisms and practitioners within the English care policy system is therefore required in order to explore this potential for inconsistent treatment and protection further.

## **4.6 Conclusion**

This review of the care policy literature has revealed the complexity of the overarching care policy system and care policy practices in England. It has enabled me to comprehensively map the English care policy environment for the purposes of my methodology by setting out the array of policy mechanisms provided by the state to meet the caring dyad's needs and risks. It also identifies the key governance arrangements used by states to help determine which risk-bearers the state deems to be eligible to access statutory support and protection. Moreover, it considers the institutional and inter-personal factors which can impact on the ability of individuals to access the statutory support that is available. However, this review highlights the need for a comprehensive and systematic empirical analysis of the English care policy environment to be undertaken in order to: assess the implications of the system's complexity on the level of statutory protection provided to risk-bearers and their ability to access it; and consider the extent to which informal care is not only recognised as a social risk by the English state but also treated as one. This requires an analysis which can capture the nuances contained within the care policy environment and how the state may treat the care-related risks of different types of care-givers and care-receivers differentially within and across different policy mechanisms, policy domains, and localities. There is also a need to analyse institutional processes in their entirety and the decision-making of actors, such as practitioners and managers, with whom informal care-givers and care-receivers must engage in order to access statutory support. This in-depth analysis will enable me to explore the extent to which the state recognises and seeks to protect different types of risk-bearers from the care-related poverty and welfare risks which they face. This in turn will facilitate consideration of whether the English state recognises and treats informal care-giving as a social risk which requires public support and protection.

# Chapter 5: Methodology

## 5.1 Introduction

This chapter sets out the research methodology underpinning this qualitative empirical study. Each element of the research process is discussed in turn in order to provide a transparent account and explanation about the choices and decisions that were made and how these supported me to answer the research questions.

The chapter is split into three key sections. The research design section sets out the philosophical and normative positioning of the thesis as an interpretivist study. It discusses the reasoning behind selecting a case study design which features comparative dimensions. It explains the case selection process, and how the unit of analysis and the policy simulation tool<sup>46</sup> were designed to facilitate the analysis of the treatment of informal care across localities, practitioners, care relationship types and policy domains. The data collection section describes the mixed methods approach that was adopted and explains how data were collected using a range of research methods including the care relationship matrix and interviews. Here, the decisions and ethical considerations relating to the recruitment of the research participants and the conduct of the interviews are discussed. Moreover, a critical analysis of the fieldwork process is undertaken. This reflexive account draws comparisons between the challenges I faced as a researcher gaining access to research participants and information, and the barriers that the research findings ultimately revealed the caring dyad to face in accessing statutory support and protection. Finally, the data analysis section explains the way in which the data were organised and qualitatively analysed using coding and thematic analysis techniques to generate the research findings. It explains what the care relationship matrix data, containing the statutory support entitlements of different types of care relationships across a range of policy domains, could expose about the state's treatment of informal care as a social risk. It also explains the governance framework that was applied to analysing the institutional structures, processes and interactions of actors within the care policy environment. Together, these two analytical strands provided the evidence with which to answer the research questions as to the extent to which the English state recognises and treats informal care-giving as a social risk which requires public support and protection.

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<sup>46</sup> The care relationship matrix.

## 5.2 Research design

### 5.2.1 Ontological, epistemological and normative positioning

This qualitative research project has been undertaken from an interpretivist philosophical standpoint. This stems from the ontological and epistemological position that there is a social reality which can be analysed but that the particular phenomenon under review can be subject to varying interpretations by social actors, which can alter over time. Consequently, interpretivism contests the possibility of neutral, unbiased observation being undertaken by researchers (Yanow, 1996, 2000). According to Yanow, researchers undertake their own sense-making about the aspect of social reality they are analysing which causes them to modify what they observe and how they interpret the meaning of their observations. This meaning-making, which affects the production of knowledge at all stages of the research process, is influenced by their own a priori knowledge of the topic and their subjective experiences emanating from their family, community and national background, education, discipline, etc. (Schwartz-Shea and Yanow, 2012). Reflexivity is therefore required on the part of the researcher to ensure they actively consider how their own experiences, characteristics and knowledge have influenced the construction of the “lens” through which they ‘see the world and makes sense of what is seen’ (Yanow, 1996, p. 6; Schwartz-Shea and Yanow, 2012). My own reflexive account about the influence that my personal and professional experiences have had on the construction of my thesis and the way I perceive, understand and interpret the issue of informal care has been discussed in Chapter 1.

Interpretivist approaches to research also encourage researchers to problematise their own “design” of the policy problem (Dryzek 1990, in Yanow, 1996, p. 15) to avoid misinterpretation of the data. For the knowledge and the “knower” producing that knowledge is context specific which allows for the possibility of reinterpretation to always exist (Yanow, 1996). This view not only extends to acknowledging the possibility that different researchers would apply a different interpretation to this issue but also that the state, wider public, and research participants may do so too. I recognise that my construction of care as a risk-based activity contains inherently negative connotations. Whereas it is evident that care-giving can be a positive experience for many people and that not all those engaged in a relationship of giving or receiving care would associate the risks that I describe with the care-giving role. Moreover, interpretive policy analysis expects research participants to vary in their perception of the phenomenon being analysed (Yanow, 1996). I needed to be mindful that the responses of the research participants may or may not support my conceptualisation of informal care as a social risk which deems it to be the state’s responsibility to protect care-givers against those risks. Their responses may challenge whether it is only when the state is involved in

providing statutory protection that a particular contingency can be recognised as a social risk. I therefore needed to remain open to recognising alternative interpretations of this phenomenon both within the research process and beyond.

### **5.2.2 Case study featuring comparative dimensions**

This research project was initially designed as a comparative study. The intention was to compare the extent to which the state treats informal care as a social risk across two national contexts. This would have entailed analysing the statutory outputs available to different types of care relationships and seeking to *explain* the similarities and differences in the states' treatment of informal care across the two cases (Hantrais, 2009; Carmel, 2012). The design of the policy simulation tool remains applicable to undertaking this type of cross-national comparison in a future piece of research. However, in order to ensure the feasibility of completing this research project within the given time-frame, it was re-designed as a single case study set within one national context. A case study design provides the following methodological advantages which are of relevance to this research. Firstly, it allows for significant flexibility in the type and scale of the unit of analysis, ranging from an individual, organisation, or policy, to a country (Denscombe, 2010). This design therefore permitted the selection of the English care policy environment as the unit of analysis. This enabled a wide range of policies, practitioners and organisations to be incorporated into the analysis which was necessary for exploring the treatment of informal care by the English state. Secondly, case studies entail an intensive investigation of a particular instance of a phenomenon, and allow for an in-depth and complex analysis to be undertaken which is capable of examining inter-connected relationships and processes (Denscombe, 2010; Bryman, 2012). This would allow policy regulations, governance arrangements, institutional structures and processes, and actors to be incorporated into the analysis thereby enabling me to examine the interacting dynamics of the entire policy system and how each component can affect the caring dyad's ability to access statutory support. Thirdly, case studies can be used inductively to discover information by describing, exploring or comparing particular settings, and deductively to test theory and explain why certain outcomes happen, and may potentially incorporate both elements (Denscombe, 2010). It also benefits from prior development of theoretical propositions to guide the data collection and analysis (Yin, 2009). This approach was therefore suitable for conducting an exploration of the treatment of informal care by the English state, based on the conceptualisation of informal care as a social risk set out in Chapter 3.

In order to achieve the overarching research objective and answer the research questions:

- How do welfare state care policies treat the care-related risks of different types of informal care-givers and the older people they care for in England?
- How far and in what ways do these policies recognise and treat informal care as a social risk which requires public support and protection?

a number of comparative dimensions needed to be incorporated into the research design. For it was necessary to assess the extent to which the state recognises and provides comparable levels of statutory support and protection to **all** types of informal care-givers and the older people they care for against the care-related risks they face. Determining which comparative dimensions to incorporate into the research design was informed by the literature review which had revealed the key institutional and inter-personal factors that could affect the consistency of support provided by states. These included: the decentralisation of government policies to local government agencies or organisations to implement which could produce territorial inequalities; the discretionary decision-making of front-line practitioners and managers which could produce practitioner-based inequalities; and the differential eligibility criteria utilised within individual policy mechanisms which could affect how individuals are treated on account of their characteristics. Each of these comparative dimensions needed to be addressed in the design of the unit of analysis and the research tools.

### **5.2.2.1 Case selection and defining the unit of analysis**

The case selection was based on a combination of purposive and theoretical sampling. This allows a case to be chosen due to it featuring specific attributes which are either of empirical relevance to the research, or theoretically meaningful for developing or testing theory (Denscombe, 2010; Mason, 1996 in Silverman, 2010). England was selected for the following reasons.<sup>47</sup> Firstly, demographic data reveal the English case to contain the key threat factors, discussed previously in Chapter 3, for informal care being recognised as a social risk by states. England has a growing older population, with 16.4 per cent of the English population being aged over 65 in 2011 (Office for National Statistics, 2013c),<sup>48</sup> a high prevalence of informal care-givers caring for older people compared to other EU countries (Gabriele et al., 2011), but also a diminishing informal care supply (Pickard, 2008). Secondly, my personal and professional familiarity with the English care policy

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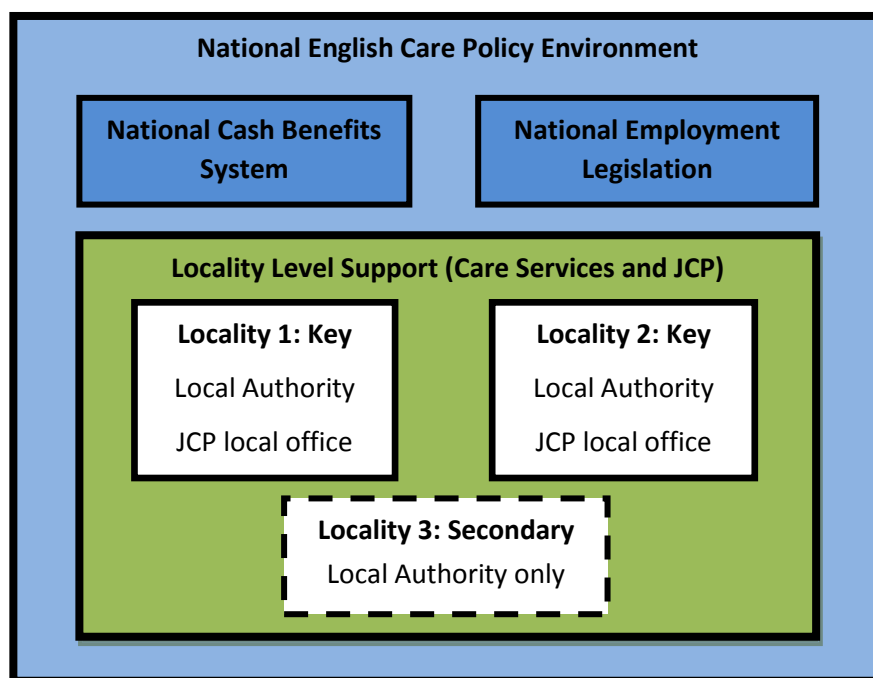
<sup>47</sup> The UK was not selected due to the devolved nature of government. As noted previously in Chapter 4, although the benefits system remains unified across the UK, the field of health and social care are devolved functions, which has led to different long-term care strategies and policies emerging across the four nations.

<sup>48</sup> This is above the average of 15.9 per cent calculated by UNDESA (2011) for other ageing 'more developed' regions.

environment together with the policy scoping exercise conducted in Chapter 4 provided a priori knowledge that England features a significant array of care policies that would make it a relevant and exemplifying case for analysing the treatment of informal care as a social risk (Bryman, 2012). Thirdly there was an element of convenience to the case selection on account of the logistical and practical advantages of conducting fieldwork in England (Denscombe, 2010). Moreover, being a native researcher would promote my understanding and interpretation of the operation of institutional systems and policies (Bradshaw, 1994; Eardley, 1996).

The English care policy environment served as the overarching unit of analysis. However additional stipulations needed to be made in designing the unit of analysis due to some policy domains featuring decentralised governance structures which had implications for the data collection process. Consequently, although the data collection for cash benefits and the statutory employment rights of care-givers could be undertaken at a national level due to being managed or devised centrally,<sup>49</sup> the data collection for the care services and Jobcentre Plus (JCP) domains needed to be undertaken at a locality level. Furthermore, more than one locality was required to allow the data to capture whether territorial inequalities exist in the statutory support provided to care relationships across different local authorities or JCP offices. Figure 10 reveals how this resulted in an embedded case study design containing sub-units of analysis in the form of policy domains and localities (Yin, 2009).

**Figure 10: The design of the unit of analysis**



<sup>49</sup> This analysis did not consider how employment policies are operationalised in practise by individual employers due to time constraints.

The localities were selected using a convenience sample based upon the local authority contacts that I had access to.<sup>50</sup> This sampling strategy was suitable because the sample was intended to be exploratory (Denscombe, 2010). Moreover, specific selection criteria were not applied because the intention of the comparison was not to explain why particular differences may exist across the specific localities selected. The resulting sample featured two key localities with differing geographical and demographic characteristics (see Figure 11) where a full range of interviews were conducted. Meanwhile, Locality 3 was categorised as a secondary locality because a single social worker contact formed the sole source of interview data for this locality. The inclusion of this locality was intended to offer further, albeit limited, insight into the extent to which territorial variations exist in the treatment of informal care in the care services domain. This would strengthen the ability of the care services research findings to comment upon the state’s treatment of informal care from a macro level perspective.

**Figure 11: Characteristics of the selected localities**

<b>Characteristics</b>	<b>Locality 1: Key</b>	<b>Locality 2: Key</b>	<b>Locality 3: Secondary</b>
<b>Type of local authority</b>	Unitary Authority Urban	County Council Rural	Unitary Authority Urban
<b>Population (approx.)</b>	300,000	200,000	400,000
<b>Proportion of population aged 65+<sup>1</sup></b>	14.5%	21%	13.1%
<b>Number of carers</b>	31,951	22,850	40,876
<b>Deprivation Index (LSOAs)</b>	17% LSOAs in top 10% most deprived areas nationally	12% LSOAs in top 25% most deprived areas nationally	12% LSOAs in top 10% most deprived areas nationally

*Source:* All information obtained from local authority sources except number of carers obtained from (Buckner and Yeandle, 2011).

*Note:*

<sup>1</sup> National average 16.4 per cent.

<sup>50</sup> One local authority was accessed via a social worker contact who was an ex-colleague, the other two were accessed via local authority contacts of one of my supervisors. The selection of the JCP offices was guided by the geographic parameters of the selected local authorities.

### **5.2.3 Mixed methods approach**

One final advantage of using a case study design is that it allows researchers to use a variety of research methods, sources of data, and quantitative and qualitative evidence (Yin, 2009). This research project adopted a ‘mixed methods’, as opposed to a ‘mixed methodologies’, approach to the research design and data collection methods (Schwartz-Shea and Yanow, 2012). This emanated from a problem-driven, pragmatist position rather than an attempt to construct the research in accordance with both epistemological paradigms (Bryman and Becker, 2012a). A number of research tools were therefore selected for gathering data from a range of secondary and primary data sources, however, the dominant methodological and analytical approach underpinning the overarching research project was qualitative. The construction of the policy simulation tool was based upon certain quantitative principles including: researcher control being maintained over the construction of the care relationship types; and a matrix being used to structure the interviews and systematically collect and analyse numerical<sup>51</sup> and non-numerical data.<sup>52</sup> However, the overriding purpose of the matrix was to expose the logics of the policy system. In addition interviews were used to obtain rich qualitative data in order to explore: the complexity of the care policy context and institutional processes; and the perspectives, interpretations and opinions of those actors engaged within the policy environment (Denscombe, 2010; Bryman and Becker, 2012b; Irvine, 2012). Using this range of research tools facilitated the analysis of the explicit and implicit treatment of informal care by the English state. They revealed the material policy output in the form of the actual statutory entitlements of each care relationship, as well as the symbolic policy output in relation to what the design and wording of policies and processes express about state intentions (Yanow, 1996).

### **5.2.4 Using policy simulation techniques**

The construction of the policy simulation tool, which took the form of a model care relationship matrix, will now be explained in detail. This research technique was selected as a policy analysis tool in order to help reveal the logics of the policy system and the extent to which the state seeks to offer consistent protection to informal care-givers and older people against the care-related welfare and poverty risks which they face. Policy simulation tools allow the extensive and diverse nature of national policy packages to be analysed in a systematic way in relation to: what is available; how it is delivered; who by; who to; for how long; and at what level (Bradshaw, 1994), from the perspective of constructed types of intended policy recipients (Kilkey, 2000). Consequently it can capture the intended effort made by states through their policies to mitigate the risks borne by particular policy

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<sup>51</sup> E.g. benefit amounts and the frequency and duration of care services.

<sup>52</sup> E.g. to indicate whether or not an entitlement would be available, or under which specific circumstances.



recipients (Eardley, 1996; Ditch et al., 1998). The construction of a standard matrix also enables rigorous and consistent comparisons to be undertaken (Bradshaw, 1994, p. 445; Eardley, 1996). It would therefore facilitate the analysis of the state's treatment of informal care across localities, practitioners, care relationship types and policy domains. It could be used to compare the statutory support entitlements of different types of care relationships, and examine the treatment of each care relationship type across different policy mechanisms and domains. This tool would therefore help to expose the policy logics underpinning the design of state care policies, and the categorisations applied by the state to determining which care-related risks and which types of informal care-givers are recognised as requiring social protection and which are left unprotected.

A key limitation of using policy simulation techniques is that it focuses on the intended outputs of policies. This produces a description of the way the system *should* work rather than how it necessarily does in practice (Bradshaw et al., 1993; Eardley, 1996; Kilkey, 2000). Even so, the primary purpose of this research project is to explore the intentions of the state as demonstrated through their intended policy outputs rather than the actual policy outputs received by care-givers and care-receivers. This is because it is the policies themselves which provide the evidence as to how states treat the needs and risks of informal care-givers and demonstrate how, or whether, they recognise informal care as a social risk. Consequently, undertaking interviews with informal care-givers and older people about the statutory support they receive were not used as the main data collection method. It would have been difficult to locate research participants with the exact configurations of characteristics to support the systematic analysis of the logics of the care policy environment. Furthermore, this method would only have provided data about what the particular individuals who were interviewed actually received in the way of statutory benefits, services and support. This may not have reflected their notional entitlements as recognised by the state, because existing research evidence suggests that informal care-givers often do not claim the statutory support that they are entitled to on account of institutional and agency-related barriers. For example, awareness of the right to request flexible working was found to be very low amongst care-givers<sup>53</sup> (The NHS Information Centre, 2010a), and care-givers reported difficulties accessing Carers Allowance and other benefits due to struggling to find relevant information about what is available and having difficulties understanding how different benefits interact (Fry et al., 2011).<sup>54</sup> Moreover, although 5.4 million informal care-givers were identified in England in the 2011 census, only 445,000

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<sup>53</sup> With only 27 per cent of employed care-givers in full-time employment and 24 per cent of those in part-time employment being aware of their rights

<sup>54</sup> This may explain why only 23 per cent of care-givers providing 35 hours of care or more are in receipt of Carer's Allowance (The NHS Information Centre, 2010a).

carers assessments were offered to informal care-givers by English local authorities in 2010-2011 (Carers UK, 2012b; Office for National Statistics, 2013a). Using a policy simulation technique in lieu of policy recipient interviews would therefore enable a specific range of care relationship types to be analysed and provide a better guarantee that each care relationship would be in receipt of their correct and complete statutory entitlement.<sup>55</sup>

#### **5.2.4.1 Methodological innovations in constructing the model care relationship matrix**

The model care relationship matrix was influenced by the model family approach whose proponents had previously used a similar type of policy simulation tool to examine income transfers for families (First pioneered by Kamerman and Kahn 1978, 1983, 1988, 1989, in Bradshaw, 1994). However, in order to achieve my specific research objectives I applied several methodological innovations to the application and construction of the policy simulation matrix. Previously, with the exception of Schunk (1996) who had undertaken a small-n case study comparing the formal care options available to frail older people in two countries, this technique has primarily been used to undertake large scale cross-national comparisons.<sup>56</sup> My intention was to apply this technique to analysing the treatment of policy recipients in a single national context. Two key innovations were also made to the construction of the matrix in relation to the policy environment and the potential policy recipients. Firstly, previous studies had used this technique to analyse the statutory support outputs available to policy recipients in a single policy domain. Whereas in this study three separate matrices were devised in order to capture a wider range of state support provided across the policy fields of cash benefits, care services and employment. Secondly, previous studies have generally constructed model family types consisting of multiple configurations of children and parents. However, this research constructed dyadic care relationship models, consisting of an informal care-giver and the care-receiver they care for. I will now go on to discuss both methodological innovations in more detail.

#### ***Constructing the care policy environment***

The construction of the care policy environment and identification of the individual care policy mechanisms found within England was supported by the policy review carried out in Chapter 4, and an extended search of government, local authority, and third sector websites and documents. Three

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<sup>55</sup> Although inaccuracies may still occur on account of researcher or research participant error.

<sup>56</sup> Of: child support packages (Bradshaw and Piachaud, 1980; Bradshaw et al., 1993; Bradshaw and Finch, 2002); the employment status of lone parents (Bradshaw et al., 1996; Kilkey, 2000); social assistance schemes (Eardley et al., 1996); and family policies (Ditch et al., 1995, 1996; 1998).

separate matrices were ultimately constructed, one for each of the policy domains under investigation. The intention was to incorporate the whole range of policy mechanisms available in order to accurately represent the overall effort made by the English state to protect informal care-givers and older people from the care-related poverty and welfare risks that they may face. Separate matrices were constructed in order to: maintain the distinction between the different policy domains; facilitate the data being collected in a systematic way; and accommodate the research data being collected at either a national or locality level across the different policy domains.

The exact policy mechanisms contained within each of the matrices can be viewed in the examples of the completed appendices provided in the Appendices, so only a brief overview will be provided here.

- The cash benefits matrix (see Appendix 4) contains all the cash transfers and other types of financial support<sup>57</sup> which may be paid to individuals on account of their care-giving role or need for care in old age. Some additional policy mechanisms are also included which do not take account of care-givers.<sup>58</sup> This is because policy ‘absences’ can indicate something equally important about the way in which states treat the risks relating to informal care.
- The care services matrix is divided into two separate charts (see examples in Appendix 5 and 6), in order to display the statutory entitlements of each member of the caring dyad in this domain. Each chart contains the key policy mechanisms which determine access to statutory support, including the legislative right to an assessment of need and eligibility bandings. The charts also incorporate the types of care services and support available across local authorities to meet individuals’ eligible needs<sup>59</sup> and whether individuals are expected to pay a financial contribution towards the cost of their care. The matrix focuses on recording what actual care services practitioners would assess individuals to need rather than how much Direct Payment money they would allocate them, because the former was the most prevalent form of care service delivery at the time of the study.<sup>60</sup> However, the matrix does record whether care-receivers and care-givers would be offered a Direct Payment since this option is a legal entitlement.
- The employment support matrix (see Appendix 7) incorporates the range of policy mechanisms available to working-aged care-givers on account of their employment status. This covers:

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<sup>57</sup> Known as passported benefits

<sup>58</sup> E.g. working tax credits and JobSeeker’s Allowance.

<sup>59</sup> This can take the form of direct local authority service provision or services which are commissioned and funded by the local authority but provided by private or third sector providers instead.

<sup>60</sup> In 2009-2010 only 10 per cent of people aged 65 and over receiving council-funded social care were in receipt of a personal budget or direct payment (Care Quality Commission, 2011, p. 34), meanwhile 74 per cent of all informal care-givers were not in receipt of their own Direct Payment (The NHS Information Centre, 2010b).

National Insurance contributions for care-givers; Jobcentre Plus (JCP) support for care-givers seeking to re-enter employment and any statutory conditions applied to them seeking work; and the legislative rights of employed care-givers. Only those employment-related support measures which employers are under a statutory obligation to provide in England are included in the matrix.

### ***Constructing the care relationship types***

Thirteen care relationship types were constructed to act as the policy recipients whose statutory entitlements were to be analysed within the matrix in order to expose the logics of the care policy environment. One noted limitation of constructing policy recipients for policy simulation purposes is their arbitrary nature, because they can only claim to be illustrative of possible types rather than representative (Eardley, 1996). In order to promote the salience of the care relationships with empirical reality and ensure their effectiveness for achieving the research objectives, their construction was informed by statistical data, eligibility criteria, and the conceptualisation of care. The process of selecting the characteristics for each care relationship was also iterative and was facilitated by undertaking a pilot interview with a benefits advisor in order to test the matrix. This resulted in the characteristics of some care relationships being revised in order to create more realistic scenarios which would help to reveal the logics of the policy system. Consequently, the construction of the care relationships required multiple decisions to be made which will be set out in detail here due to the significance of these decisions for ensuring relevant data were obtained with which to answer the research questions.

The focus of the thesis is on the treatment of informal care-givers by the state. However, the literature review chapters all highlighted that the inter-relational nature of care is a key consideration to understanding and analysing care. For example, in Chapter 2 the feminist literature noted how recognising the relational dimension of care is essential for the practice of an ethics of care; in Chapter 3 the inter-related nature of the care-related risks experienced by care-givers and care-receivers was highlighted; and in Chapter 4 it was noted how the statutory care support that is available to support care-givers often takes the form of replacement care services which are provided directly to the care-receiver. Consequently, in order to accurately capture the treatment of informal care and informal care-givers by state care policies it was necessary to incorporate both members of the care relationship into my analysis. The dyadic design would enable the statutory entitlements of both care-givers and care-receivers to be identified and analysed in the matrix. It would also facilitate an analysis of whether state policies, processes and actors recognise the

relational dimensions of care, and the extent to which the risks of both members are treated equally or in conflict with one another. Adopting a dyadic approach to undertaking care-related research is commonly found within the care literature. However, some researchers have noted that overreliance on this type of modelling noting that dyadic constructions fail to recognise the more dynamic and complex nature of informal care-giving. For in addition to one-to-one care relationships, many-to-one, one-to-many and reciprocal care relationships are also noted to exist, involving complex care networks in which multiple people make multiple contributions to meet the care needs of their older friends and relatives (Cantor, 1991; Sims-Gould et al., 2008; Rutherford, 2012; Szinovacz and Davey, 2013).

Each care relationship type was constructed using a configuration of selected characteristics (see Figure 12). The characteristics selected for inclusion were determined by several factors including: the key eligibility criteria used within English policy regulations to determine the categories of individuals deemed eligible to access care-related statutory support; and statistical evidence about care-givers in England.<sup>61</sup> Moreover, the selected characteristics were categorised into primary and secondary characteristics according to their significance in relation to care-related risks and the concept of social risk. Schunk (1996) warns against selecting too many characteristics due to the proliferation of configurations undermining the viability of the analysis by making it too complex and time-consuming. The more assumptions and choices that are made about the characteristics can also result in the constructed policy recipients being less representative of the actual population being studied (Kilkey, 2000). Consequently the configurations of characteristics were distilled down to construct 13 care relationship types intended to reflect the heterogeneous nature of informal care-giving and expose the policy logics contained within the care policy environment. The sets of configurations for each care relationship were compiled in the form of vignettes in order to facilitate their operationalisation for the data collection phase (see Appendix 1). Vignettes provide a descriptive scenario which can be used to find out how research participants would respond to a specific situation or set of circumstances (Bryman, 2012). In this study the vignettes provided a more user-friendly 'mini biography' for each care relationship to support policy experts and practitioners in assessing their entitlements to state support.

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<sup>61</sup> A key source of data was the Survey of Carers in Households (SCH) conducted in 2009-2010 (The NHS Information Centre, 2010a). The majority of care-givers who participated in the survey were providing care to older people (63 per cent), however it should be noted that others in the sample were caring for working-aged adults and children.

**Figure 12: Primary and secondary characteristics to construct the care relationship types**

<b>Primary Characteristics</b>	<b>Age of care-giver</b>	Below pension age (25-60)		Above pension age (65+)		
	<b>Income/savings levels</b>	Lowest income		Lower income		
	<b>Level of care provided/required</b>	Constant 168 hours	Daily 35 hours		Weekly 16 hours	
<b>Secondary Characteristics</b>	<b>Relationship of care-giver to care-receiver</b>	Son/ Daughter	Spouse		Other relative	Neighbour/ Friend
	<b>Marital status</b>	Single (never married, divorced, widowed)			Married	
	<b>Living arrangements</b>	Co-resident			Living separately	
	<b>Employment status</b>	Full-time care-giver	Employed		Unemployed and seeking work	Retired
	Full-time worker		Part-time worker			

### ***Selecting the Characteristics***

The data that were used and decisions that were made in selecting each of these characteristics will now go onto be justified.

### **Age of the care-giver<sup>62</sup>**

This characteristic consisted of two selected age bandings: care-givers of pension age (aged 65 and over) and care-givers of working age (aged between 25 and 60). As noted in Chapter 3, both groups are statistically significant to the provision of informal care in England (Young et al., 2006; Glendinning et al., 2009, p. 74). Moreover, they are of analytical significance due to the differential risks they may experience, with older care-givers being more likely to have their own health problems (Fry et al., 2011) and working-aged care-givers facing risks associated with attempting to

<sup>62</sup> The age of the care-receiver in each care relationship was assumed to be 65 or above. The intention was to assess their eligibility to access Attendance Allowance rather than the more generous disability benefits available to people under the age of 65 (e.g. Disability Living Allowance now Personal Independence Payment).

reconcile work and care. Both groups also experience distinctive treatment in the benefits system. It was necessary to avoid too many age-related permutations to ensure the manageability of the matrix. Consequently a specific age range was applied to the working-aged care-givers because different cash benefit amounts and types can apply to people above and below these age thresholds.<sup>63</sup> Although individuals aged 80 and over are also eligible to receive additional financial support,<sup>64</sup> the amounts are negligible and did not therefore warrant the creation of an additional age banding.

### **Level of care**

This characteristic was selected in order to assess the state's treatment of care-givers providing, and care-receivers requiring, different levels and types of care. These care-related characteristics are used by the state to determine access to care-related cash benefits and to assess individuals' eligibility bandings for accessing statutory care support. Three levels of care were devised due to care intensity being highlighted in Chapter 3 as a significant factor for contributing towards: working-aged care-givers' poverty risks by restricting their ability to engage in the labour market; and care-givers experiencing welfare risks as a result of time poverty. The evidence presented in Figure 13 was used to set the parameters of each care level banding and should be read in conjunction with the care relationship vignettes which present the resulting details about the type and level of care support provided by the care-giver and the type of generic health problem affecting the care-receiver (see Appendix 1).

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<sup>63</sup> For example, means-tested benefits have different rates for individuals under and over the age of 25, and men aged between 61 and 65 can currently choose between claiming working-aged benefits such as Income Support/JSA or Pension Credit. This can have implications for accessing passported benefits because different savings limits and tariff incomes apply.

<sup>64</sup> In their Basic State Pension and Winter Fuel Allowance.

**Figure 13: Evidence used to construct care level bandings**

Level of care	Type and level of care needs and care provision
<p><b>Constant care</b> 168 hours per week</p>	<ul style="list-style-type: none"> <li>The constant care relationships represent the most burdened care-givers at critical risk of experiencing care-related risks.</li> <li>Vlachantoni's (2010) analysis of ELSA data found that just over one fifth of informal care-givers aged 50+ provide round the clock care.</li> <li>SCH data found informal care-givers providing 20+ hours of care per week were more likely to be: caring for someone with either a mental health problem or mental and physical health problems; providing personal care and physical help (The NHS Information Centre, 2010a).</li> </ul>
<p><b>Daily care</b> 35 hours per week</p>	<ul style="list-style-type: none"> <li>The daily care relationships represent those care-givers at substantial risk of experiencing care-related risks.</li> <li>The SCH data described above were used to determine the type of care provided in these care relationships.</li> <li>The level of care was set at 35 hours per week because:               <ul style="list-style-type: none"> <li>this is an equivalent time commitment to a full-time job</li> <li>access to Carers Allowance requires this level of care to be provided.</li> </ul> </li> </ul>
<p><b>Weekly care</b> 16 hours per week</p>	<ul style="list-style-type: none"> <li>The weekly care relationships represent those care-givers with a moderate risk of experiencing care-related risks.</li> <li>The majority of care-givers in England provide under 20 hours of care per week (The NHS Information Centre, 2010a; Vlachantoni, 2010).</li> <li>SCH data found care-givers providing under 20 hours of care per week were more likely to be: caring for someone with a physical health problem; and providing help with administrative tasks and social support on a weekly or monthly basis (The NHS Information Centre, 2010a).</li> <li>Increasingly states do not provide this type of domestic support (Lundsgaard, 2005).</li> <li>The level of care was set at 16 hours per week because:               <ul style="list-style-type: none"> <li>this is an equivalent time commitment to a part-time job. Studies show providing 14-15 hours of care per week acts a threshold for having negative impacts on labour market participation (Spiess and Schneider, 2002; Gabriele et al., 2011).</li> <li>it falls outside the remit for claiming Carers Allowance and Carers Credits (20 hours per week);</li> <li>it has implications for having to actively seek work.</li> </ul> </li> </ul>

Key to Colour Code <sup>65</sup>	Care relationships
Tier 1 care relationships: constant (168 hours per week)	CR1, CR4, CR7, CR10
Tier 2 care relationships: daily (35 hours per week)	CR2, CR5, CR8a, CR8b, CR11
Tier 3 care relationships: weekly (16 hours per week)	CR3, CR6, CR9, CR12

<sup>65</sup> This colour code is applicable to the vignettes in Appendix 1 and all the matrices.



### Financial circumstances and employment status

The financial circumstances (income and savings levels) of care-receivers and care-givers are often used by state policies to determine access to cash benefits and care services and to calculate care service charges. Two financial sub-categories were applied to this characteristic - a lowest income and a lower income banding - in order to assess the state's treatment of those care relationships most at risk of poverty. SCH data show approximately 51 per cent of care-givers to live in households with an income of less than £20,800 (The NHS Information Centre, 2010a). The specific income and savings levels set for each of these bandings were devised in conjunction with the employment status of the care-giver and the level of care provision. These characteristics helped to guide and explain the financial circumstances of each care relationship. Moreover, the relational status of the caring dyad also had to be taken into account in order to determine whether the care relationship's financial circumstances are calculated as two single individuals or a married couple with a joint income and savings. Figures 14 and 15 summarise the income and savings levels that were set in order to ensure that the lowest income care relationships would be eligible to receive means-tested benefits, while the lower income care relationships would be excluded from this type of benefit entitlement, respectively. Consequently, the savings levels of the lowest income care relationships were set below £6,000 because in the UK benefit system the first £6,000 are disregarded in any means-tested benefit assessment. Moreover, the care-givers of working age have no income due to the assumption that they are not currently engaged in paid employment, although the care-giver providing 16 hours of care per week is assumed to be actively seeking work.<sup>66</sup> Meanwhile the care-givers over pension age and all the care-receivers are assumed to be retired and to have an entitlement to a Basic State Pension (BSP) only. The maximum amount of BSP an individual can receive is £107.45 per week, and £171.85 for married couples.<sup>67</sup> Due to these income levels being below the personal allowances set by the government,<sup>68</sup> it would ensure that all these individuals are entitled to Guarantee (Pension) Credit and passported benefits.

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<sup>66</sup> This assumption is supported by 2001 Census data which showed 131,000 care-givers to be unemployed and actively looking for work (Fry et al., 2011). SCH data also found that among care-givers caring for under 20 hour per week 24 per cent were interested in taking up paid employment (The NHS Information Centre, 2010a).

<sup>67</sup> This joint pension amount is based upon the assumption that the couple assumed traditional gender roles during their working-aged lives resulting in the husband being in receipt of a Category A BSP based on a full NIC record (£107.45 per week) and the wife receiving a Category B reduced state pension derived via her spouse's NIC record (£64.40 per week).

<sup>68</sup> £142.70 per week for single pensioners and £217.90 per week for pensioner couples (2012-2013).

**Figure 14: Configurations of characteristics for lowest income care relationship types**

Personal circumstances	Age	Care-receiver over pension age (65+) Care-giver under pension age (25-60)			Care-receiver and care-giver over pension age (65+)		
	Relationship of care-giver to care-receiver	Son/daughter	Son/daughter	Son/daughter	Spouse	Spouse	Sibling/ Friend/ Neighbour
	Marital Status of care-giver	Single	Single	Single	Married	Married	Single
	Marital Status of care-receiver	Widowed	Widowed	Widowed	Married	Married	Single/ widowed
	Level of care per week	168 hours	35 hours	16 hours	168 hours	35 hours	16 hours
	Living arrangements	Living in same household	Living in separate household	Living in separate household	Living in same household	Living in same household	Living in separate household
	Employment status	Not working	Not working	Unemployed and actively seeking work	Retired	Retired	Retired
	Financial circumstances	Savings levels	Under £6,000	Under £6,000	Under £6,000	Under £6,000	Under £6,000
Care-receiver's weekly income	BSP (£107.45)	BSP (£107.45)	BSP (£107.45)	Total £171.85: Husband: BSP (£107.45) Wife: reduced state pension (£64.40)	Total £171.85: Husband: BSP (£107.45) Wife: reduced state pension (£64.40)	BSP (£107.45)	
Care-giver's weekly income	£0	£0	£0			£0	
Property	Rented	Rented	Rented	Rented	Rented	Rented	
Care relationship type	1	2	3	4	5	6	

Figure 15 shows the savings levels of all the lower income care relationships are set at £16,000, which is £1 above the upper savings limit for entitlements to most means-tested benefits. In relation to income levels, the care-givers over pension age and all the care-receivers are assumed to be retired and in receipt of a Category A or B Basic State Pension depending on their marital status, with an additional income also being derived from an occupational pension (OP).<sup>69 70</sup> Consequently, their resulting income levels are set above the threshold for an entitlement to Guarantee (Pension) Credit.

<sup>69</sup> Using median occupational pension rates taken from the Pensioner Incomes Series data for 2009-10 (Department for Work and Pensions, 2011a, p. 41).

<sup>70</sup> The gender and exact marital status of the single care-receivers and care-givers is not specified. However, the BSP and OP pension amounts given are deemed to be applicable to: men and never married women who are assumed to have worked full-time; and widows who would be entitled to a Category A BSP rate based on their deceased husband's full NIC's record (Primmer, S., (Simon.Primmer@PensionsAdvisoryService.org.uk), 2012) and who generally continue to receive the occupational pension as the surviving spouse (Mitchell, 2011, p. 50).

**Figure 15: Configurations of characteristics for lower income care relationship types**

	Age	Care-receiver over pension age (65+) Care-giver under pension age (25-60)				Care-receiver and care-giver over pension age (65+)		
	<b>Personal circumstances</b>	Relationship of care-giver to care-receiver	Son/daughter	Son/daughter	Son/daughter	Son/daughter	Spouse	Spouse
Marital Status of care-giver		Single	Single	Married	Single	Married	Married	Single
Marital Status of care-receiver		Widowed	Widowed	Widowed	Widowed	Married	Married	Single/widowed
Level of care per week		168 hours	35 hours	35 hours	16 hours	168 hours	35 hours	16 hours
Living arrangements		Living in same household	Living in separate household	Living in separate household	Living in separate household	Living in same household	Living in same household	Living in separate household
Employment status		Not working	Working part-time	Not working	Working full-time	Retired	Retired	Retired
<b>Financial circumstances</b>		Savings levels	£16,000 each	£16,000 each	Each household £16,000	£16,000 each	Joint savings £16,000	Joint savings £16,000
	Care-receiver's weekly net income <sup>1</sup>	£186.45: BSP (£107.45) and OP (£79)	£186.45: BSP (£107.45) and OP (£79)	£186.45: BSP (£107.45) and OP (£79)	£186.45: BSP (£107.45) and OP (£79)	Total £311.00: Husband: BSP (£107.45) plus OP (£166)	Total £311.00: Husband: BSP (£107.45) plus OP (£166)	£186.45: <sup>2</sup> BSP (£107.45) and OP (£79)
	Care-giver's weekly net income (after tax and NIC deductions)	£203.73	£203.73 Annual net salary = £10,594.12	Care-giver income = £0 Spouses income = £534.38 Annual net salary = £21,427.54	£203.73 Annual salary = £10,594.12	Wife: reduced state pension (£64.40)	Wife: reduced state pension (£64.40)	£186.45: BSP (£107.45) and OP (£79)
	Property	Both own their own property	Both own their own property	Both own their own property	Both own their own property	Own their property	Own their property	Both own their property
<b>Care relationship type</b>	<b>7</b>	<b>8a</b>	<b>8b</b>	<b>9</b>	<b>10</b>	<b>11</b>	<b>12</b>	

Note:

<sup>1</sup> Tax calculations undertaken using tax rates for married couples aged 65-74 for 2012-2013 (Lewis, 2012).

<sup>2</sup> The income of these single pensioners is exempt from tax because the tax allowances in 2012-2013 for people aged 65-74 and 75+ were £10,500 and £10,660 respectively (Directgov, 2012a).

The income levels of the lower income care-givers of working age were based upon more complex assumptions. They were intentionally set below the median income level<sup>71</sup> but above the UK government's poverty line. This was to ensure that these care-givers would not be entitled to

<sup>71</sup> The Annual Survey of Hours and Earnings calculated that the median gross weekly earnings for full-time employees in the UK in April 2011 was £498 (Office for National Statistics, 2012a).

means-tested benefits<sup>72</sup> but could still be deemed at risk of poverty due to not having an adequate amount to live on.<sup>73</sup> To determine the issue of adequacy the Minimum Income Standard (MIS) compiled by the Joseph Rowntree Foundation was used (Hirsch, 2011). This specified that a single person working full-time would require a wage of £7.67 per hour or a weekly budget of £240.89 per week to achieve a minimum socially acceptable standard of living in 2011. The National Minimum Wage rate of £6.08 per hour<sup>74</sup> was therefore used as the baseline for calculating the net income of the lower income care-givers at £203.73 per week. Figure 16 shows the additional employment data that were used to explain care-givers' income levels.

**Figure 16: Evidence used to construct circumstances of lower income care-givers of working age**

Personal characteristics	Care-givers' financial and employment circumstances <sup>1</sup>
<b>CR7:</b> Working-aged, single care-giver, providing constant care	<ul style="list-style-type: none"> <li>• Net income = £203.73 per week generated from renting out their empty property.</li> <li>• The intensity of their care-giving is assumed to prevent them from having time to engage in paid employment.</li> </ul>
<b>CR8a:</b> Working-aged, single care-giver, providing 35 hours of care per week	<ul style="list-style-type: none"> <li>• Net earnings = £203.73 per week based on working part-time (16 hours per week @ £14.25 per hour) in either an associate professional or technical occupation, such as a chiropodist, IT technician, or plumber (This is Money, 2011; Pike, 2012).</li> <li>• SCH data found care-givers providing more than 20 hours of care per week more likely to be working part-time than full-time.</li> <li>• Census data (2001) showed 675,000 care-givers to be working part-time (Fry et al., 2011).</li> </ul>
<b>CR8b:</b> Working-aged, married care-giver, providing 35 hours of care per week	<ul style="list-style-type: none"> <li>• Care-giver is not in paid work nor in receipt of any other income.</li> <li>• Their spouse works full-time (37.5 hours per week @ £14.25 per hour) in an associate professional or technical occupation with net earnings of £412.07 per week.</li> <li>• The couple have joint savings of £16,000.</li> </ul>
<b>CR9:</b> Working-aged, single care-giver, providing 16 hours of care per week	<ul style="list-style-type: none"> <li>• Net earnings = £203.73 per week based on working full-time (37.5 hours per week @ £6.08 per hour) in either an elementary or sales and customer service occupation (PayScale, 2012; Pike, 2012).</li> <li>• Census data (2001) showed 1.5 million care-givers to be working full-time (Fry et al., 2011).</li> </ul>

Note:

<sup>1</sup> All Tax and NI deductions calculated using (Listentotaxman.com, 2012) based on 2012-2013 tax year.

<sup>72</sup> This calculation also needed to factor in the tariff income applied to savings by the state, with £1 for every £250 of savings between £6,000 to £16,000 being applied to working-aged individuals, and £1 for every £500 of savings above £10,000 being applied to pensioners (Child Poverty Action Group, 2012).

<sup>73</sup> Care relationship 8b is the exception and was incorporated in order to analyse a slightly more affluent household and assess how a care-giver's marital status can impact on their statutory entitlements.

<sup>74</sup> For adults aged 21 in 2011-2012 (Gov.uk, 2014a).

## Secondary characteristics

Secondary characteristics were also selected and incorporated into the vignettes in order to humanise the care relationship biographies. They included: the relational status of the care-receiver and care-giver; their living arrangements; and their marital status. These details were also necessary for working out the care relationships' statutory entitlements because these characteristics often feature within the eligibility criteria of policy regulations. Different configurations of these secondary characteristics were applied in order to capture the relational diversity of care relationships in England. These choices were informed by the empirical evidence listed in Figure 17 and certain pragmatic considerations. For example, determining whether the members of the caring dyad were living together was pre-determined to a greater extent by the intensity of the care being provided and the provision of spousal care. Moreover, more single care-givers were constructed than married care-givers due to their higher potential risk of experiencing poverty and welfare risks noted in Chapter 3.

**Figure 17: Evidence to support selection of secondary characteristics**

<b>Relational status of the caring dyad</b>	
<b>Working-aged carers as filial carers</b>	<ul style="list-style-type: none"> <li>• Pickard et al. (2007) found the most important source of informal care in England for single older people is their children</li> <li>• 90 per cent of those providing 20+ hours of care to parents are under the age of 65 (Pickard, 2008).</li> </ul>
<b>Pension-aged carers as spousal carers</b>	<ul style="list-style-type: none"> <li>• Pickard et al. (2007) found the most important source of informal care in England for married older people is their spouse</li> <li>• Care-givers aged 65+ are the most likely age group to say they are caring for their spouse (The NHS Information Centre, 2010a; Vlachantoni, 2010).</li> </ul>
<b>Pension-aged carers as siblings/friends/neighbours</b>	<ul style="list-style-type: none"> <li>• Among care-givers aged 70-79, 34 per cent were providing care for other relatives, friends and neighbours (Vlachantoni, 2010).</li> <li>• Siblings/friends/neighbours are the fastest growing source of informal care in England (Pickard et al., 2012).</li> </ul>
<b>Living arrangements of the caring dyad</b>	
<b>Living together</b>	<ul style="list-style-type: none"> <li>• 75 per cent of care-givers providing 20+ hours of care a week live in the same household as the care-receiver (Pickard, 2007).</li> <li>• The co-residence of care-givers increases in line with a rise in care intensity (Vlachantoni, 2010).</li> </ul>
<b>Living separately</b>	<ul style="list-style-type: none"> <li>• 48 per cent of the care undertaken in a separate household is for a parent compared to 19 per cent of the care undertaken in the same household (The NHS Information Centre, 2010a).</li> <li>• Only 9 per cent of care-givers aged 50+ caring for a relative, friend or neighbour live with the care-receiver (Vlachantoni, 2010).</li> </ul>
<b>Marital Status</b>	
<b>Married and single carers</b>	<ul style="list-style-type: none"> <li>• The probability of adult children providing intensive care (20+ hours per week) to older parents in England is higher for single people</li> <li>• But the total numbers of married care-givers is higher (Pickard, 2008).</li> </ul>

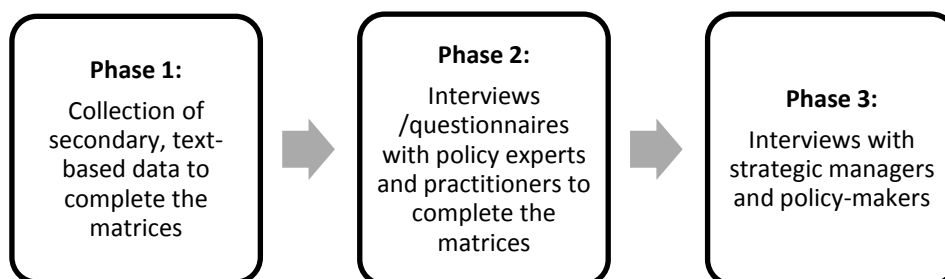
### Excluded Characteristics

Certain characteristics were intentionally excluded from the construction of the care relationships for a number of reasons. Firstly, the specific medical diagnosis of the care-receiver was not stipulated because eligibility is more frequently determined by the level of need or care. Consequently, only a generic health condition was incorporated into the vignettes to grant practitioners the freedom to consider whether any specific health conditions would impact on their decision-making about individuals' statutory entitlements. Secondly, care-givers were assumed to have good health status, even though 1 in 4 care-givers report having a limiting long-term illness of their own (Pickard, 2007). This was to promote the manageability of the analysis and to avoid assessing the care-givers' disability-related entitlements as well as their care-related entitlements. Lastly, the gender of both members of the caring dyad was not specified because this characteristic is not explicitly used within policies as a category to determine eligibility to state support. Consequently, in most cases applying this additional characteristic would have resulted in a duplicate set of results. However, in order to address whether practitioners in the care services domain take characteristics such as gender, the care-giver's mental or physical health state and the quality of the care relationship into account within their decision-making about statutory entitlements, these factors were incorporated as additional questions in the interview schedule.

### 5.3 Data collection

Figure 18 sets out the distinct phases of the data collection process undertaken for this study. Secondary data were gathered from a range of text-based sources meanwhile primary data were also obtained by undertaking interviews. The purpose was to obtain straightforward factual data (Denscombe, 2010) as well as gain an understanding of decision-making processes affecting access to statutory support. One advantage of using multiple sources of evidence is that it can produce overlapping data checks which provide an element of systematic rigor to qualitative research (Schwartz-Shea and Yanow, 2012).

**Figure 18: Data Collection Phases**



### 5.3.1 Data collection methods

The desk-based research undertaken during Phase 1 involved accessing pre-existing online data about care policy mechanisms and their eligibility criteria and using these data to complete elements of the cash benefits and employment support matrices. A range of data sources were utilised including: government;<sup>75</sup> third sector (Carers UK, 2011b, 2012a; Child Poverty Action Group, 2012; Age UK, 2012a,b); and private sector (e.g. energy suppliers) documents and websites. These data enabled me to determine: which of the care relationship types would be eligible to access particular types of statutory support in these domains; and, if applicable, how much statutory support they would be entitled to access.<sup>76</sup> An online benefits calculator assisted with undertaking the more complex benefit calculations (Turn2us, 2012).

Phase 1 of the data collection process was supplemented, and in certain cases verified, by the data gathered during Phase 2.<sup>77</sup> Phase 2 involved conducting interviews with experts and practitioners from each policy domain,<sup>78</sup> with a view to achieving several objectives. Firstly, the interviews acted as a form of checking mechanism to ensure the care relationships' statutory entitlements calculated using the aforementioned secondary data did not contain errors. Misrepresenting or misinterpreting policies is a potential risk when using policy simulation techniques (Kilkey, 2000). Using experts who understand the intricacies of care policy regulations and governance arrangements, including whether receipt of one type of statutory support precludes receipt of another, can help to reduce these risks. Secondly, these interviews also provided primary data for completing the matrices, particularly in relation to the care services and JCP domains. For as noted in Chapter 4, practitioner decision-making can be critical to determining individual's statutory support entitlements in these domains. Considerable researcher control was retained over standardizing the format of these interviews because they were structured using the vignettes and matrices. The care relationship types were described in a set order and the policy mechanisms listed in the matrix were used to prompt practitioner responses. This promoted consistency across the practitioner interviews and ensured that a completed matrix was produced from each interview.<sup>79</sup> However, practitioners were also provided with the opportunity during the interviews to explicitly

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<sup>75</sup> This included legislation and guidance documents, application forms for cash benefits (Department for Work and Pensions, 2010, 2011b,c), and websites including Direct.gov.uk (now replaced by www.gov.uk), Carers Direct and www.nhs.uk.

<sup>76</sup> All the collected data related to the financial year 2012-2013.

<sup>77</sup> All Phase 2 and 3 interviews carried out in 2012.

<sup>78</sup> In some cases participants opted to respond in writing to the interview questions. This was accommodated by converting the interview schedule into a questionnaire format which was emailed out as a Word document, thereby allowing them unrestricted space to write their responses.

<sup>79</sup> Only one practitioner lacked the level of expertise required to complete a matrix (L2LAP3).

discuss their decision-making. This was facilitated by using vignettes which reduce the possibility of interviewees providing unreflexive responses (Bryman, 2012). Supplementary semi-structured interview questions were also used as prompts to elicit more discursive information (see example: Appendix 2). This extracted richer, more in-depth data about the treatment of different care relationship types. It helped to explore the institutional processes in which practitioners operate and the extent to which their decision-making resists or subverts official policy intentions (Barnes, 2012) or applies different policy meanings to different policy recipients (Yanow, 1996).

The Phase 3 interviews were conducted with individuals who have a strategic brief for carers, either in relation to lobbying on behalf of carers as representatives of third sector organisations; or devising/delivering strategies or policies as local or national government level employees. Semi-structured interviews were conducted to obtain these specialists' interpretations about the treatment of informal care and informal care-givers by state policies and processes.<sup>80</sup> The national level interviews with senior experts were conducted towards the end of the fieldwork. This ensured that the formulated questions and my interview performance were strengthened by the knowledge acquired about the policy environment from undertaking Phase 1 and 2 of the data collection and analysing the national carer strategies (Department of Health, 1999, 2008, 2010c). The pre-determined list of interview questions were individually tailored according to each research participant's institutional positioning. However, interviewees were permitted flexibility in the sequence in which the interview questions were covered and were able to speak more widely about any specific issues raised which were of interest to them (Denscombe, 2010; Irvine, 2012).

### **5.3.2 Selecting and accessing the research participants**

A mapping exercise was carried out in order to determine the variety of people required to provide multiple perspectives on the research topic (Schwartz-Shea and Yanow, 2012). This type of purposive sampling strategy enables participants to be strategically selected based on their relevance for obtaining the best information for answering the research questions (Flick, 2009; Denscombe, 2010; Bryman, 2012). This research project required research participants from across a range of policy domains, government agency and third sector organisations; offering practitioner, operational and strategic manager perspectives; at a local and national level. Individual participants were selected in their capacity as experts with specific professional knowledge and experience about the institutional policies and processes relating to informal care (Flick, 2009; Denscombe, 2010). An

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<sup>80</sup> Although fewer interviews with third sector strategic managers were conducted than intended due to the requests made to one organisation eliciting no response.



additional sampling consideration was that the locality-based interviews required equivalent samples of participants in order to fulfil two of the comparative elements of the research design. To explore territorial inequalities, participants with similar roles from equivalent agencies needed to be recruited across the two key localities. To explore practitioner effects on the policy outputs of care relationships, interviews with several front-line practitioners needed to be undertaken in each local authority. A purposive sampling strategy was successfully applied to accessing some research participants, who responded to the written requests sent via email to their respective organisations. Access to other research participants was achieved using a snowball sampling technique. This type of strategy relies upon 'initial' research contacts acting as gate-keepers in providing access to additional participants in the relevant field (Denscombe, 2010). It has the advantage of ensuring that those who are nominated are likely to be interested in, and relevant to, the research (Denscombe, 2010). This strategy proved to be particularly helpful for gaining access to front-line practitioners in the local authorities. It was also essential for recruiting JCP representatives, access to whom was ultimately gained using the professional networks of a Benefits Agency manager and a local authority strategic manager. The final sample of 26 research participants is listed in Appendix 3.

The challenges I experienced as a researcher during the fieldwork process in terms of accessing relevant research participants and institutional information replicated to varying degrees some key findings about the care policy system which emerged from the research data. Multiple barriers were encountered relating to institutional capacity, opacity and complexity issues, as well as disinclination and knowledge deficits on the part of institutional actors. Time constraints contributed to practitioners refusing to participate in the research across more than one sector. For example, several social worker contacts cited being 'overwhelmed' by work; JCP advisors were noted by one DWP gatekeeper to be too busy to participate; and a local third sector carers' organisation did not participate on account of 'capacity issues'. Gaining access to the Benefits Agency and Jobcentre Plus also proved to be particularly difficult due to the organisational opacity of these statutory agencies, with some institutional gate-keepers lacking either the knowledge or willingness to forward my information onto prospective participants. The lack of transparency about the organisational structure of these agencies forced me to resort to cold calling local JCP offices and publically listed DWP telephone numbers, and sending email requests to DWP public email accounts in an attempt to find an institutional entry point. This led to contact with the JCP press office, who in response to my request to interview Benefits Agency and JCP personnel, referred me to the Directgov website and provided erroneous advice to contact the Department of Health for information about JCP support

for carers and the DWP care partnership manager role. Ultimately two of my speculative emails successfully reached two willing DWP managers who were instrumental in giving me access to relevant personnel. Even so, their support in this endeavour did not always produce research participants. Several potential participants across various sectors declined to participate due to perceiving themselves to lack sufficient knowledge. This reason was given by a JCP care partnership manager who recommended I contact a carers' organisation instead, and a local carers' organisation, with the welfare reform changes also being cited as an impediment for finding a benefits advisor who could answer my questions. Meanwhile, institutional complexity affected finding a representative from a local authority carers' team, and a carers' policy expert from a national organisation, to interview. Both situations necessitated me making repeated follow up contact with multiple gatekeepers in each organisation. In one case my persistence did finally result in an interview, however my other request eventually petered out along an extended chain of institutional gatekeepers. Institutional factors and personal preferences also affected the mode in which research participants were willing to provide their information, with a number of statutory agency participants<sup>81</sup> only agreeing to complete the interview schedule as a questionnaire. The reasons given included a lack of time to be interviewed; a preference to respond in writing due to the complexity of the answers; and not having institutional permission to give interviews where the information would subsequently be available in the public domain. The distance this placed between myself and the participants resulted in the collected data being limited to factual details about institutional policies and processes rather than providing insights into participants' opinions and decision-making processes.

Many of the institutional and inter-personal barriers which I encountered during my fieldwork were ultimately revealed by my research data to be similar to those affecting informal carers and older people attempting to navigate through the care policy system to gain access to their statutory entitlements. For example, the caring dyad's awareness of, and ability to access, statutory support can be diminished by the complexity and lack of transparency of the policy environment. Moreover, the institutional gatekeepers they encounter or are allocated are often critical to their success or failure to access support. This outcome is often dependent upon the gatekeeper's institutional knowledge, and their willingness to share information and undertake negotiations on the caring dyad's behalf. The opacity of institutional systems and secrecy of decision-making processes can present overwhelming barriers for risk-bearers to overcome, made worse by the fact that informal carers often lack the personal resources required, in the form of time and energy, to persist in trying

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<sup>81</sup> From JCP, Benefits Agency, and LA1.

to penetrate and navigate these systems and processes. Added to which institutional resource constraints are increasingly restricting access to statutory support and making the system progressively more impenetrable to both care-givers and care-receivers in need of support. Consequently, my fieldwork experiences inadvertently provided me with the opportunity to better understand the institutional experiences of care relationships in England.

### **5.3.3 Ethical considerations**

It is essential to conduct social research in an ethical way in order to ensure that no harm is done to those individuals participating in or associated with the research (Hardwick and Worsley, 2011; Banks, 2012). This commitment is required whether the research involves research participants who hold positions of power, such as policy-makers and practitioners, or vulnerable and disadvantaged groups (Social Policy Association, 2009). Researchers must reduce the risk of exposing the research participants to avoidable harm by: ensuring that they are able to give their informed consent to participate in the research; protecting their identify; and avoiding deception (Hardwick and Worsley, 2011; Banks, 2012). Each potential research participant was therefore provided with an information sheet which set out the purpose of the study and explained their role and rights within the research process. This included information about: the duration, content and context of the interviews; privacy clauses about how their data would be used, stored and anonymised;<sup>82</sup> and notification about their right to withdraw themselves or their data from the process up until the project's submission. Copies of the interview schedules were also sent out in advance. All the research participants were asked to read and sign their consent on the information sheet. Due to conducting interviews about the state's treatment of potentially vulnerable groups of people, research participants were verbally advised of the limits of confidentiality at the start of the interview (Banks, 2012).<sup>83</sup>

The need to protect the anonymity of the research participants also extended to consideration of the location of the interviews. This was because most participants were being interviewed in their professional capacity as employees of government agencies who could potentially hold critical views about statutory polices and processes. Moreover, some senior staff who had either granted institutional permission to undertake the interviews or been interviewed had also expressed an

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<sup>82</sup> All the interviews were digitally recorded. The recordings together with the interview transcriptions and questionnaires were stored securely on a password protected computer. Code names were used to protect the identity of the research participants and the localities in which they worked.

<sup>83</sup> If any disclosures were made about personal or institutional practices which had safeguarding implications for themselves or third parties a referral may be made to an appropriate agency.

interest in seeing the thesis findings. Consequently all interviewees were provided with a choice as to where their interviews took place. Several practitioners requested the interviews were conducted in their own homes, while others opted to book a private room at their office base. The responses provided by research participants can potentially be affected by the location of the interview, as well as their perception of the interviewer (Denscombe, 2010). The research participants were made aware that the research was being conducted for the purpose of my PhD. My professional background and informal carer status was not disclosed. Even so, several interviewees in one local authority were aware that I had previously worked there as a social worker, in two cases the research participants were ex-colleagues. The extent to which any of these factors affected the research participants' responses during the interviews is difficult to discern. The more significant factor in hindsight appeared to be the institutional positioning of interviewees, with practitioners providing more critical views about the treatment of informal care by statutory agencies than managers.

## **5.4 Data analysis**

### **5.4.1 Organising the data**

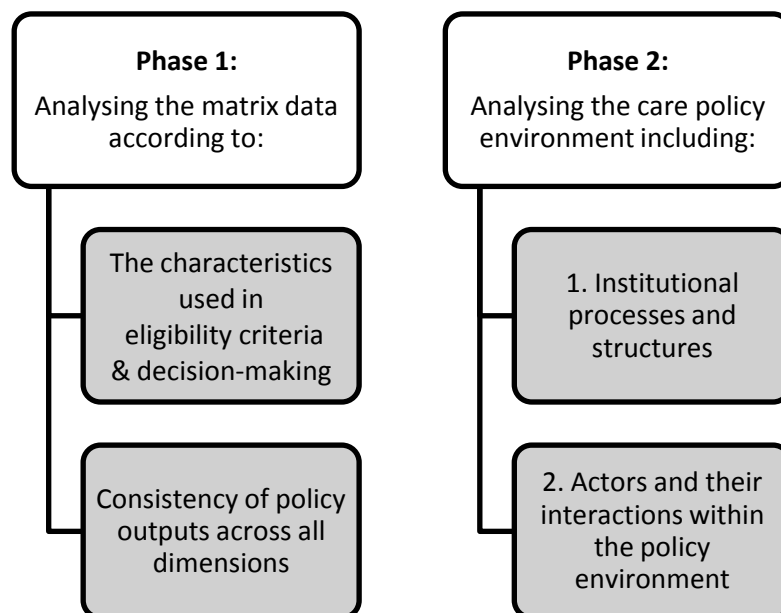
It was necessary to organise the collected data into manageable formats prior to being able to undertake the data analysis. The data pertaining to each care relationship's statutory entitlements was collated in two ways. Firstly, nine completed matrices were produced including: one cash benefits matrix reflecting the nationally applied criteria (see Appendix 4); six care services matrices, one per generic or specialist practitioner interview (see examples: Appendix 5 and 6); and two employment support matrices, one reflecting each of the JCP practitioner interviews (see example: Appendix 7). Secondly the additional in-depth qualitative data, obtained through the transcribed interviews, 'questionnaires' and policy documents about each care relationship's entitlements, were also collated. This involved disaggregating the relevant data obtained from the various sources and practitioner interviews, reorganising them under each specific care relationship type (e.g. CR1, CR2 and so on) and sub-dividing the data by individual policy mechanisms. Both sets of data supported the identification of similarities and differences in the policy outputs and treatment of informal caregivers and older people across care relationships types, domains, practitioners and localities. The institutional processes through which individuals gain access to statutory support also needed to be analysed. This required all relevant data from across the various data sources to be similarly collated under the different institutional processes, such as assessment and resource allocation processes in the care services domain, and the processes through which carers request flexible working or access

JCP support, in the employment support domain. This data preparation provided a more manageable framework for undertaking the qualitative analysis.

### 5.4.2 Analytical phases

Two distinctive data analysis phases were undertaken, both of which utilised qualitative analysis techniques (see Figure 19). This dual approach supported the analysis of the state’s treatment of informal care from a micro and macro level perspective.

Figure 19: Phases of analysis



#### 5.4.2.1 Phase 1: Analysing the matrix data

The matrix data were analysed qualitatively instead of statistical analysis being applied. The intention was not to calculate and compare the generosity levels of the statutory support and protection provided to different care relationships types. Instead an interpretive policy analysis approach was applied to analysing the matrices and the associated in-depth qualitative data in order to expose the logics of the English care policy environment in its treatment of informal care. Interpretive policy analysis considers how policy presences and policy absences can constitute both material and symbolic expressions of public values and beliefs about a particular issue (Yanow, 1996). With policy entitlements revealing which types of citizens are awarded the status of legitimate claimants for government action (Yanow, 1996). Findings were generated through *the process* of determining the policy entitlements of each care relationship type using policy and

practitioner data, and analysing their resulting policy outputs. This helped to reveal which characteristics the English state uses to determine access to statutory support and protection in relation to informal care and which types of informal care-givers and care-related risks are recognised to warrant that protection. Analysing the care policy environment from the micro-level perspective of policy recipient's entitlements helped to reveal the extent to which the English state recognises and treats informal care as a social risk. Where gaps exist in statutory protection, leaving particular groups or care-related risks unprotected, it reveals the state to only partially recognise and treat informal care as a social risk. The results of this analysis form the basis for Chapter 6.

#### **5.4.2.2 Phase 2: Analysing institutional structures, processes and actors**

The second data analysis phase involved undertaking a macro level analysis of the English state's treatment of informal care and informal care-givers. This element of the analysis was influenced by the 'governance analysis' approach developed by the Governance Research Group (GRG) at the Department of Social and Policy Sciences, University of Bath (Carmel, 2014).<sup>84</sup> Although my analysis did not apply the GRG's 'critical analytical perspective' (Carmel, 2009) in its entirety, key features of it were used to construct a systematic framework for collating my data and structuring the analysis chapters. The GRG governance approach seeks to analyse the relationships between institutional structures, processes and actors and examine the institutional, social and political effects these dynamic interactions can have (Carmel, 2014). My intention was to examine how the construction of the care policy environment and the interactions of actors engaged within it, give rise to the inconsistent treatment of informal care-givers discussed in Chapter 6 and can help to explain the state's treatment of informal care overall. Chapter 7 therefore focuses on critically analysing the institutional structures and processes contained within each of the care policy domains. This in depth analysis highlights key trends and weaknesses in the statutory provision that is available for care relationships and helps to reveal the wider structural positioning of informal carers within the policy system. Meanwhile Chapter 8 examines the interactions of key actors as they seek to negotiate the complexity of the care policy environment and considers how they shape the practice of public policy (Carmel, 2014). This reveals the inter-personal and institutional barriers which the members of the caring dyad can face, both directly and indirectly, when attempting to access the statutory protection that is available.

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<sup>84</sup> The group was led by Dr. Emma Carmel and included the following members: Hannah Durrant, Michelle Farr, Jenny Harlock, Hester Kan, Sarah Morgan-Trimmer, and Regine Paul.

These collated data were analysed using thematic coding techniques. The raw data were broken down and conceptualised through a process of increasing abstraction and refinement. This involved initially identifying individual concepts within the data, and subsequently identifying patterns and trends which could be grouped into categories and more abstract themes (Corbin and Strauss, 2008; Flick, 2009; Gibbs, 2012). This inductive approach enables the detail of the data to be thoroughly analysed and processed until analytical saturation is reached and more generalised statements about the topic are generated (Denscombe, 2010). This coding process permitted trends to be identified in how informal care is treated by the English state and the implications of its treatment for those engaged within the policy environment. The data were organised and coded using Microsoft Word rather than a specialist analytical software package such as NVivo. Diagrams were also used to instil analytical distance from the data in order to draw out the overarching themes and conceptual relationships (Corbin and Strauss, 2008). The overall data analysis process entailed multiple iterations. Although this was laborious, it provided the opportunity to gain a thorough knowledge and understanding of the data and ensured that I did not 'rush to (an analytical) diagnosis' in the interpretation of the data and identification of patterns and themes (Schwartz-Shea and Yanow, 2012, p. 105). Due to the amount of data, the data pertaining to the institutional processes contained within each policy domain were initially coded separately. The emerging trends identified in each policy domain were subsequently re-analysed to determine whether particular concepts and categories were replicated across the policy domains as common analytical themes in the state's treatment of informal care (Yin, 2009). Meanwhile the analysis of the negotiation processes undertaken within the care policy environment entailed identifying: categories of institutional and inter-personal factors which can affect actor's interactions within these processes; and the effects that these interactions can have upon the social relations of actors. This led to themes emerging relating to the emotional landscape of the overarching care policy environment. This thematic coding enabled greater analytical abstraction to be achieved in analysing the treatment of informal care by the English state.

## **5.5 Conclusion**

This chapter has provided an overview of the methodology which was designed and applied to answering the research questions. A detailed account of the research process has been produced to promote transparency in the design and manner of its conduct and to facilitate the assessment of the quality of the research by comprehensively analysing the strengths and weakness of the methodological approach. The discussion of the fieldwork challenges that I experienced also helps to reiterate the meaningfulness of the research findings that will now go onto be discussed, which

reveal the institutional and inter-personal barriers that the caring dyad can face when attempting to navigate access to, and negotiate through, the care policy system. The impact that my own personal and professional experiences have had on the construction of the thesis, my interpretation of the topic, and the design, collection and analysis of the data, have also been considered. Although interpretive approaches risk accusations of researcher bias (Corbin and Strauss, 2008), I consider my background experiences to have been critical for constructing and operationalising a rigorous and coherent research project. It has also provided me with sufficient insight for generating possibilities of meaning during the analysis phase and offered me a degree of resilience when faced with analysing such a complex policy area. The next three chapters set out my analysis of the collected research data.



## **Chapter 6: Characteristics affecting statutory entitlements of the caring dyad**

### **6.1 Introduction**

This initial analysis chapter analyses the research data collected using the care relationship matrix and associated interviews in order to examine the extent to which the state, through its policies and practitioners, recognises the poverty and welfare risks that individuals who are involved in the provision and receipt of informal care face. This helps to expose that the state does not recognise or treat all care-givers and care-receivers equally. Instead only certain types of care relationships and individuals are categorised as being eligible to receive statutory support and protection against the care-related risks that they face, meanwhile other risk-bearers are excluded from this protection.

This chapter seeks to expose and explain the state's inconsistent treatment of different types of care relationships by analysing how the state applies particular characteristics or configurations of characteristics to determine access to statutory support across the cash benefits, care services and employment support domains. A nuanced analysis is undertaken of: the way in which some characteristics are weighted within eligibility criteria as being more significant than others; and how the significance of a specific characteristic can vary considerably across policy domains, policy mechanisms, localities, practitioner decision-making and according to which member of the caring dyad it is being applied to. Moreover, the transparency of the application of these characteristics is also examined as to whether they are used by the state implicitly or explicitly, inclusively or exclusively, directly or indirectly to determine individual's entitlements. This analysis reveals that a key implication of the state's inconsistent treatment of characteristics is that inequalities are produced in the level of statutory protection different types of carers, care-receivers and care relationships can receive. This results in the care-related risks of some groups being socialised while other group's poverty and welfare risks are unprotected and therefore remain either partially or fully privatised. These findings make a significant contribution to revealing the extent to which the English state recognises and treats informal care as a social risk. For this thesis argues that for a state to recognise and treat informal care as a social risk it would require all risk-bearers to be recognised and adequately protected against all of the care-related risks that they face.

This chapter is structured as follows. Section 6.2 identifies the key characteristics explored in the analysis. Section 6.3 details how the significance of particular characteristics has been assessed.

Section 6.4 analyses the state's treatment of each individual characteristic in turn. Here, the commonalities and differences in the application of each characteristic and the relative weighting of their significance across policy domains, policy mechanisms and practitioner decision-making are identified. The effects that this treatment can have for different types of carers and care-receivers are exposed, by identifying those groups whose risks are protected by the state and those whose risks are left unrecognised and privatised. Section 6.5 considers which particular characteristics are most significant overall for granting the members of the caring dyad access to statutory support. The contribution these findings make to the thesis as to what this reveals about the extent to which the English state treats informal care as a social risk is also discussed.

## **6.2. Identifying the key characteristics**

Figure 20 illustrates the key characteristics which are used by the state to determine the caring dyad's access to statutory support in the cash benefits, care services and employment support domains. It incorporates those primary<sup>85</sup> and secondary<sup>86</sup> characteristics identified in Chapter 5 which were used to construct the care relationship types and which were already known to be significant. The remaining characteristics including the gender and health condition of members of the caring dyad, the impact of the caring role on the carer and the quality of the care relationship, emerged from the interview data. Colour coding is used to demarcate these individual characteristics according to whether they feature as: the care-giver's characteristics; the care-receiver's characteristics; or the inter-relational characteristics of the caring dyad.

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<sup>85</sup> Income/savings levels; the level of need required/level of care provided; the age of the carer.

<sup>86</sup> The caring dyad's: living arrangements; relational status and relational proximity; marital status; the carer's employment status.

**Figure 20: Categorising the key characteristics used to determine the caring dyad's eligibility to statutory support**



Key to colour code
Care-receiver's characteristics
Care-giver's characteristics
Inter-relational characteristics of the caring dyad

### 6.3 Determining the level of significance of individual characteristics

The level of significance of each characteristic for determining access to statutory protection across the three policy domains has been rated according to whether it is significant; less significant; or insignificant (Figure 21). This grading system has taken a number of factors into account. Firstly, the consistency with which the characteristic is applied across each policy domain in relation to its presence or absence within the eligibility criteria of policy mechanisms and practitioner decision-making. If a characteristic is explicitly used in a consistent way across all policy mechanisms and by all practitioners it is deemed to be significant. Meanwhile inconsistent use across practitioners or policies leads it to be demoted to a less significant characteristic. Secondly, the extent to which a characteristic is either explicitly or implicitly used within the regulations and decision-making has been considered. Explicit use of a characteristic awards it more significance due to it revealing the state’s purposeful intent to treat a characteristic in a particular way. Thirdly, consideration has been given to whether a characteristic plays a subordinate rather than a primary role in determining eligibility. A characteristic may also be considered subordinate if it has a seemingly inadvertent or indirect impact on the statutory entitlements of particular types of individuals.

**Figure 21: Rating the significance of characteristics**

Level of Significance	Defining features
<b>Significant Characteristic</b>	<ul style="list-style-type: none"> <li>• The specific characteristic is explicitly contained in the legislation and regulations of all policy mechanisms within the policy domain;</li> <li>• And/or all practitioners consistently reveal this characteristic to be significant in their decision-making</li> </ul>
<b>Less Significant Characteristic</b>	<ul style="list-style-type: none"> <li>• The significance of the characteristic only applies to a few policy mechanisms within the policy domain;</li> <li>• And/or there is a lack of consistency across practitioner’s responses as to how significant the characteristic is to their decision-making;</li> <li>• Or the characteristic is not explicitly used in the eligibility criteria or practitioner decision-making but is found to implicitly impact on access to statutory entitlements;</li> <li>• Or the characteristic is classed as a subordinate characteristic due to eligibility being primarily affected by other characteristics.</li> <li>• Or the characteristic has an inadvertent or indirect impact on access to statutory entitlements.</li> </ul>
<b>Insignificant Characteristic</b>	<ul style="list-style-type: none"> <li>• The specific characteristic is not contained explicitly or implicitly within the eligibility criteria of policy mechanisms;</li> <li>• And/or the characteristic has no direct or indirect impact on practitioner decision-making</li> </ul>

Alongside specifying the level of significance of particular characteristics, this analysis also considers how the state’s treatment of different characteristics can be subcategorised further as to whether

characteristics are subject to contradictory, anomalous or inconsistent treatment by state policies and practitioners. These variations can occur across localities as well as across practitioners and policy regulations thereby permitting territorial inequalities as well as individual, dyadic, and group based inequalities to emerge. It is important to identify and acknowledge this differential treatment due to it having different implications for the treatment of informal carers and informal care by the state. All of these nuances will be considered in more detail throughout section 6.4.

## 6.4 Evaluating the significance of individual characteristics for accessing statutory entitlements

The matrix results (see examples in Appendix 4, 5, 6, 7) reveal which care relationships are considered eligible to access each particular type of statutory support available within the cash benefits, care services and employment support domains. It is the differential treatment of characteristics by state policies and practitioners that results in differential statutory outputs being available to different care relationships and some care relationships being excluded from accessing particular types of care-related statutory protection altogether. The significance of each characteristic will now be analysed in turn in order to explain these unequal statutory outputs. Throughout this section the care relationship types will often be referred to by their ‘tier’, as set out previously in Figure 13, Chapter 5 and reproduced here.

Care Relationship Tiers	
<b>Tier 1:</b> Constant (168 hours per week)	CR1, CR4, CR7, CR10
<b>Tier 2:</b> Daily (35 hours per week)	CR2, CR5, CR8a, CR8b, CR11
<b>Tier 3:</b> Weekly (16 hours per week)	CR3, CR6, CR9, CR12

### 6.4.1 Level of care, type of care and impact of caring

Figure 22 reveals how the level and type of care, and to a lesser degree the impact of caring, constitute the most significant characteristics used in both policy regulations and practitioner decision-making for determining the caring dyad’s access to statutory support and the level of statutory protection they receive. However, inconsistency in the application of these characteristics occurs across policy mechanisms and localities as well as across the members of the caring dyad. Both the type of care tasks which are categorised to be legitimate for activating a statutory response, and the level of care support an individual needs to provide or receive in order to access

statutory protection are subject to variation. Meanwhile, the subjective measure of the impact of caring sometimes takes precedence within decision-making. The ambiguity of this characteristic permits extensive levels of practitioner discretion and contention. So although the prevalent trend is for Tier 1 and Tier 2 care relationships containing high need care-receivers and full-time carers to receive the greatest level of statutory protection, inequalities can still emerge in the statutory outputs of care relationships. Consequently, the care-related risks of Tier 3 low need care relationships are not consistently privatised.

**Figure 22: Significance of the characteristics of level, type and impact of care provision**

Characteristic	Cash Benefits	Care Services		Employment	
		Care-receiver (CR)	Carer (C)	JCP Support	Employment policies
Level/type of need of CR	Significant (AA,CA,CC, IS)	Significant	Less significant (practitioner variation)	Less significant (indirect)	Less significant (implicit)
Level/type of care provision by carer	Significant (CA,CC, IS/JSA)	Less significant (practitioner variation)	Significant	Significant	Less significant (implicit)
Impact of caring role	Less significant (IS only)	Less significant (practitioner variation)	Significant	Less significant (practitioner variation)	Not significant

#### 6.4.1.1 Inconsistent treatment of the level and impact of care

The level of need of the care-receiver and the level of care provided by the carer are explicitly used as key characteristics for determining which care relationship types can access disability and care-related benefits. However, while care-receivers' access to Attendance Allowance (AA) is determined solely by their level of need, which enables all high need Tier 1 and Tier 2 care-receivers to access AA, carers' access to Carers Allowance (CA) is dependent on the complex intersection of a wider number of characteristics. Consequently, not all 'full-time' carers are ultimately eligible to receive a CA payment because access to CA is affected by the characteristics of age and earnings in addition to the level of care provided. Moreover, access to all carers' benefits, including CA, Income Support (IS) and Carers Credit (CC), is contingent upon the care-receiver being eligible to access AA. Therefore it is ultimately the care-receiver's level of need which takes precedence in determining the carer's access to their own statutory entitlements. Even so, the level of care plays a significant role in excluding individuals who are not deemed to require or provide a substantial enough level of care from accessing all these elements of statutory financial support. This leaves the care-related poverty risks of all Tier 3 low need care-receivers and part-time carers unrecognised and unprotected by the state.

The level of care that caring dyad members must either provide or require to access CA and AA respectively is subject to inconsistent statutory treatment, with care-receivers being subject to less stringent requirements. The AA regulations only make a general specification that the care-receiver needs attention from another person on a *frequent* basis<sup>87</sup> or continual supervision<sup>88</sup> on a daily basis. In contrast carers' eligibility to access CA is subject to a significantly higher and more specific care level threshold. Consequently only carers providing a minimum of 35 hours of care *consistently every week* are categorised by the state as 'full-time' carers who are recognised to require statutory protection from the current and extended poverty risks associated with their caring role. This rigidity fails to recognise those carers providing significant levels of support to people with fluctuating or unpredictable conditions. The level of care also influences the level of statutory protection eligible individuals can receive, although again inconsistencies are revealed across each members' benefits. AA benefits rates reflect a degree of cumulative financial protection according to the care-receiver's level of need: those requiring care during the *day and night* receive £77.45 per week; those requiring care during the *day or night* receive £51.85 per week.<sup>89</sup> In contrast Carers Allowance is paid at a flat rate of £58.45 per week, which fails to distinguish between the financial risks of providing different levels of care. Consequently high need care-receivers receive more statutory protection against the poverty risks they face than carers providing an equivalent amount of care. Discrepancies are also found across the eligibility criteria of different carers' benefits as to the level of care provision deemed to warrant access to statutory protection. 'Part-time' carers, providing 20 hours of care or more per week to *one or more* individuals, are entitled to access the Carers Credit scheme which provides some protection against their extended poverty risks. In contrast, access to CA requires carers to provide at least 35 hours of care in relation to *only one* care relationship. Carers' poverty risks are therefore treated inconsistently by the state in relation to both the level of care and the structuring of the time spent caring.

Carers' access to Income Support (Department for Work and Pensions, 2012, BDWPM2), JCP employment support,<sup>90</sup> and carers assessments (HM Government, 1995; Department of Health, 2001, pp. 25–26) is explicitly determined by whether they are providing a 'substantial amount of

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<sup>87</sup> 'Frequent' is defined as several times throughout the day, or prolonged and repeated attention of at least 20 minutes, twice during the night

<sup>88</sup> 'Continual' supervision does not have to be constant but should be more than just occasional supervision (Carers Direct, 2012c).

<sup>89</sup> Figures for 2012-2013.

<sup>90</sup> Access to JCP support requires the carer to be spending 'a significant proportion of their life providing unpaid support' (Department of Health, 2008), with DWP regulations recommending this takes into account '....any caring responsibilities that are a barrier to work and will impact on the type of paid work a carer can undertake' (BDWPM2).

care on a regular basis' or 'significant' levels of care; with the characteristic of the impact of caring being used in the policy regulations to gauge whether a carer meets these criteria. The ambiguity of these terms and subjective nature of these characteristics permits inconsistencies to emerge in the level of statutory protection carers receive due to eligibility decisions being subject to agency and practitioner discretion and misinterpretation. For example, several interviewees applied unnecessarily high care level thresholds to determining carers' access to IS and JCP support services by mistakenly assuming eligibility to be solely contingent upon carers being in receipt of CA which was considered the only admissible evidence of their carer status (L1JCP1/L1TS2M/BTSP1).<sup>91</sup> This misinterpretation of the regulations could have substantive consequences for low income carers providing lower, yet still significant, levels of care. Exclusion from claiming IS would require these carers to access Job Seeker's Allowance (JSA) instead, with its stringent conditionality and lack of protection against care-related costs.<sup>92</sup> Inconsistencies could also occur in carers gaining access to carers' assessments due to divergent interpretations of the regulations being applied by local authorities. For some local authority policies had replicated the Carers Allowance regulations in restricting access to carers' assessments to 'full-time' carers providing at least 35 hours of care per week.<sup>93</sup> In contrast LA1 and LA2's policies used the impact of caring to determine eligibility rather than an absolute level of care.

*'...[W]e don't have a number of care hours in our interpretation....because it depends how much time they have available in the first place. If they are caring for 6 hours a week but actually that's the only free time they have because they work long shifts, they've got children....then they are as regular and substantial as somebody who is living with the person possibly' (L1LAM3);*

*'...[W]hat is substantial for one person might not be for another....And in terms of regular we've said it doesn't have to mean frequent', 'it's about how you as an individual cope with it all' (L2LAM2).*

These local authority policies therefore extended access to carers' assessments to carers providing lower levels of care. However, individual practitioners were found to apply different interpretations

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<sup>91</sup> Receipt of CA can be used as evidence of their substantive 'full-time' caring role. However Benefit's Agency Decision Makers are also permitted by DWP guidance (Department for Work and Pensions, 2012) to determine eligibility according to 'the impact [of caring] on the claimant's own life' taking into account: the pattern, duration, predictability and type of care provided; '....the proportion of the claimant's life and the life of the person being cared for that is taken up by the care'; and 'how disruptive the caring is to the claimant's life' (BDWPM2).

<sup>92</sup> For example, unlike carers on IS, one interviewee expected part-time carers on JSA (CR3) to privately fund their own replacement care arrangements when attending a job interview instead of providing statutory funding (L1JCP1).

<sup>93</sup> Noted by L2LAM2 and L1LAM3 in relation to other local authorities.



to the terms 'regular' and 'substantial', resulting in carers having unequal access to carers' assessments within, as well as across, local authorities.

*'...My interpretation of substantial care is if the carer is living with the person they care for and are providing 24 hour care support. Regular care is if the carer is popping in every day (L1LAP1);*

*'...10 minutes a day could be regular and substantial to someone who's got....other commitments.....' (L1LAP2);*

*'...a carer's assessment is an entitlement regardless of how much care you are putting in....even if they are just picking up their next door neighbour and taking them to the supermarket once a month...' (L2TS1M1).*

Consequently, while some practitioners considered all carers to be eligible to access a carer assessment, others excluded 'part-time' Tier 3 carers from having any entitlement, often making this decision inappropriately contingent upon the care-receiver's level of need, assuming the carer's needs to be 'low because the parent's needs are low' (L1LAP1/L2LAP2).

In the care services domain, the level and impact of care are also significant for practitioners determining how much statutory support an individual requires. However inequalities emerge across the statutory outputs of caring dyad members within and across localities due to practitioners privileging different care characteristics within their decision-making. In LA1 generic practitioners<sup>94</sup> are primarily influenced by the level of care provided by the carer or required by the care-receiver when determining the eligibility bandings and levels of statutory support care relationships can receive. For example, the high need Tier 1 care-receivers were all assessed by practitioners to require four domiciliary care visits per day of equivalent length (L1LAP3/L1LAP2/L1LAP1). Using this characteristic provided an element of consistency and uniformity in the statutory support offered to similar types of care relationships. However it ensured that 'part-time' Tier 3 carers were universally relegated to either minimal statutory intervention or complete exclusion from statutory support. Meanwhile, the decision-making of specialist carer assessors in LA1 and LA2 and 'generic' practitioners in LA2 was dominated by consideration of personalisation objectives, with the specialist practitioners being significantly influenced by the impact of the caring role on the carer. The individualising effects of more personalised approaches exacerbate inconsistency across the statutory support outputs of care relationships. For example, it led to greater diversity in the structure and size of care-receivers' care packages because practitioners noted that they would tailor the level of support provided according to the specific outcome an individual wants to achieve

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<sup>94</sup> I define generic practitioners as those undertaking assessments of both care-receiver's and carer's needs.

(L2LAP1/L2LAP2). Moreover, the eligibility outcomes of carers did not conform to any distinctive patterns, with each carer being considered to have the potential to meet a low through to a critical eligibility banding (L1LAM3).

*'.....it entirely depends on the individual.....the impact its having on them really....I mean you could have somebody who is living with their mother, doing stuff 24/7 and that could meet substantial, or you could have somebody who has got some mental health problems who is just phoning once in an evening but the effect it is having on the carer makes them substantial'* (L2TS1M1).

The flexible working regulations are a policy mechanism outlier in their treatment of the characteristic of the level of care because this characteristic is used implicitly by the state to determine eligibility rather than explicitly being used in the regulations. Carers are assumed to utilise the level of care they provide to gate-keep themselves in relation to activating this statutory 'right'. For a government consultation document noted that no employee would request a permanent change to their employment contract unless they were providing a substantial and regular amount of care due to the income reduction ramifications of instigating such action (HM Government, 2006a, p. 8).

#### **6.4.1.2 Inconsistent and contradictory treatment of different types of care tasks**

Discrepancies exist in the cash benefits and care services domains in the type of care tasks state policies and practitioners recognise to be eligible for warranting a statutory response. Personal care tasks are unanimously accepted as legitimate care activities for eliciting statutory intervention. However, inconsistency exists in the extent to which the state considers domestic care tasks to be a private rather than a statutory responsibility. Domestic care tasks are treated in contradictory ways across care-receivers' and carers' benefit entitlements. For example, the AA regulations explicitly exclude domestic tasks from their eligibility criteria,<sup>95</sup> whereas the CA and IS regulations recognise tasks such as cooking and the time spent preparing for, and clearing up after a visit from the care-receiver as eligible care tasks (Carers Direct, 2011c). This contradictory treatment is replicated in the care services domain where carers' access to statutory support tends to be determined by the level and impact of care irrespective of the type of care tasks undertaken. In contrast local authority policies and practitioners predominantly use the need for personal care to determine care-receivers' access to statutory support. Consequently in both localities, practitioners unanimously assessed all

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<sup>95</sup> Except if the care-receiver needs; help with laundry due to incontinence; help with cleaning if visually impaired; help with shopping if communication difficulties (Carers Direct, 2012c).

Tier 1 and Tier 2 care-receivers to be eligible to access statutory support on account of needing support with personal care tasks on a regular basis. Meanwhile, all Tier 3 care-receivers were considered ineligible due to primarily requiring 'assistance with domestic tasks' (L2LAP1/L2LAP2/L1LAP3/L1LAP1). This is despite the legislative framework permitting local authorities to provide 'practical assistance in the home' such as meals and laundry (HM Government, 1968, 1970, 2006b), and statutory guidance recommending eligibility decisions are based on the seriousness of the risk to independence and well-being if the care-receiver's 'presenting' needs are not addressed (Department of Health, 2003a, 2010a). Moreover, the views of other interviewees exposed this treatment of the different types of care to be contentious terrain. Local authority managers and a third sector specialist assessor considered help with domestic care tasks to constitute a legitimate care need (L1LAM3/L2TS1M1).

*'I mean you don't have to have personal care needs in order to be eligible, that's a popular myth but that is not true, the eligibility is around a risk assessment.....what's the risk to that older person if needs around housework, shopping aren't met and the risks could be very high indeed.....become unhygienic, starve to death....'* (L2LAM1).

Moreover, the research data revealed that the treatment of domestic care tasks by practitioners as a private rather than statutory responsibility was not absolute and could be significantly affected by the presence or absence of an informal carer. For example, practitioners noted that if Tier 3 care-receivers had no informal carer they were more likely to assess them to be eligible to access statutory support with their personal *and* domestic care needs (L1LAP3/L1LAP2/L1LAP1); and that Tier 1 and Tier 2 care-receivers could be provided with statutory support with domestic care tasks if they lived alone (L1LAP1/L2LAP1/L2LAP2). However, where the caring dyad lived together practitioners generally assumed that the carer would provide all the meals (L2LAP1/L2LAP2/L1LAM1/L1LAP3/L1LAP1), with only one practitioner considering the negative implications this assumption could have for live in carers not being able to access a carer break (L1LAP2).

These findings highlight an inherent contradiction in the way in which carers' needs for statutory support are treated due to different care-related characteristics being used to determine the eligibility of different caring dyad members. For although carers' benefit regulations are more generous in allowing domestic care tasks to be factored into carers' claims for statutory financial protection, carers remain significantly affected by the more restrictive regulations applied to the care-receivers' disability benefits due to the derived nature of their benefit entitlements. Similarly, although specialist practitioners recognise a wide range of care tasks when determining carers'

eligibility to statutory care support in their own right, within the care-receiver’s assessment process practitioners are more likely to treat carers as a resource due to the tendency to treat domestic care tasks as a private responsibility. This contradictory treatment ultimately undermines the level of support provided to carers in their caring role which is highly dependent on the replacement care services and cash benefits provided to the care-receiver.

## 6.4.2 Income

Figure 23 reveals how the characteristic of income constitutes a significant determinant for how the members of the caring dyad are treated in some domains but not in others. It is the characteristic subject to the most variable treatment by the state. It affects access to statutory support in both explicit and implicit ways. It is treated inconsistently across policy domains, localities, caring dyad members, and care-giver and care-receiver types, resulting in significant territorial and intra-dyadic inequalities emerging. A significant feature of this variability is the application of contradictory regressive and universal approaches. This can lead to the poverty risks of caring dyad members and different types of care relationships being treated inequitably to one another, and at times anomalously to the logics of the overarching system. These inconsistencies can significantly impact on the extent to which different types of carers and care relationships can access statutory protection against the financial risks they face and contribute to individual and intra-relational conflicts and dilemmas occurring.

**Figure 23: Significance of the characteristic of income**

Characteristic	Cash Benefits	Care Services		Employment	
		Care-receiver (CR)	Carer (C)	JCP Support	Employment policies
Income of Care-receiver	Less Significant (Means-tested benefits only)	Significant	Not significant	Not significant	Not significant
Income of Carer	Significant (CA, IS/JSA, WTC)	Not significant	Less significant (LA variation)	Not significant	Less significant (implicit)

### 6.4.2.1 Inconsistent treatment of income

Care-receivers and carers are subject to contradictory universal and means-tested approaches to determine their eligibility to statutory support across the cash benefits and care services domains. This creates disparities between members of the caring dyad and care relationships on account of their income status, in relation to the state protection they can access, and their service choices. Furthermore, some regulations contain regressive features which exacerbate income inequalities by

undermining the level of statutory protection provided to those care relationships most at risk of poverty.

In the cash benefits domain, access to AA is entirely based on an assessment of care needs rather than financial means. Consequently even the most affluent care-receivers are entitled to receive this type of financial protection from the state to compensate them for their disability-related costs. Carers' access to statutory financial protection on the other hand is significantly affected by their income status due to CA being subject to an income test. However, the CA regulations treat different sources of income inconsistently, as well as anomalously to the rest of the cash benefit system. This leads to the financial risks of different care-giver types being subject to unequal statutory treatment. Consequently more affluent non-working carers (CR7) can access CA because no limit is applied to the amount of savings or **unearned** income a carer can receive. In contrast potentially low income carers with an **earned** income of more than £100 per week (CR8a) are excluded from accessing this financial protection from the state. This exclusion applies even if an employed carer continues to provide at least 35 hours of care per week which would significantly constrain their ability to increase their earning capacity. This lack of recognition by the state of the financial risks faced by carers situated at the intersection of low income and employment contributes towards the privatisation of financial risks by those least able to afford it.

These differential approaches are reversed in the care services domain. The overarching social care system for eligible care-receivers is operated as a means-tested system, while in my particular research sites statutory support for carers is subject to a more universal approach. Consequently, care-receivers are subject to differential treatment on account of their income status, leaving statutory support primarily the domain of less affluent care-receivers. For although any care-receiver who meets the needs based eligibility criteria are legally entitled to access statutory care support regardless of their income level, and the national financial charging policy regulations take affluent care-receivers into account (Department of Health, 2003b), in practice local authorities categorise this group as 'self-funders'.<sup>96</sup> The tendency of local authorities to encourage self-funders to make their own private care arrangements was institutionalised in both localities through the development of brokerage systems which assist in identifying suitable resources from the social care market. Arranging care privately was considered by practitioners to provide 'self-funders' with the following advantages: they can purchase cheaper services compared to the charges applied for an

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<sup>96</sup> Defined as those with savings above £23,250 (Carers Direct, 2012d).

equivalent statutory care package; and they can exercise increased choice and control over the care tasks they commission,

*'[T]hey can ask the agency to do the ironing and wash up.....which we can't, we would only provide personal care and the meals' (L1LAP2).*

Even so, 'self funders' face increased administrative responsibilities when managing their own care arrangements. This in turn can increase the welfare risks and time poverty risks experienced by their informal carers. Meanwhile less affluent care-receivers who have access to statutory funding towards care services have the ability to choose how much care management support they receive from the local authority with administering their care package.<sup>97</sup> However, local authority charging policies can contribute to inequalities emerging across this group of less affluent care-receivers due to regressive flat rate charges being applied to certain types of statutory services.<sup>98</sup> These charges, which operate anomalously to the usual logics of the means-tested social care system, contribute to lower income individuals incurring proportionately greater financial costs than more affluent care-receivers.<sup>99</sup> In addition to these financial charges exacerbating the poverty risks of lower income individuals they also have the potential to produce intra-dyadic conflict, because the amount of statutory support provided will 'really be shaped by how much [the care-receiver] would be willing to pay' (L2LAM2). Consequently, if care-receivers reduce the level of replacement care services they are willing to receive on financial grounds this can simultaneously undermine the ability of their carers having a break from their caring role.

The extent to which carers' access to statutory support is affected by their financial circumstances varies considerably across localities due to local authorities having a discretionary power to charge carers for the statutory care services they receive (HM Government, 2000; Department of Health, 2003b, p. 22). My two research sites, exempted carers from financial charges thereby granting all *eligible* carers universal access to statutory support services regardless of their income status. However, other local authorities were reported to have implemented either regressive flat-rate charges for specific carer services,<sup>100</sup> or means-tested charging policies,<sup>101</sup> leading to inequalities and

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<sup>97</sup> Options range from the local authority managing the care-receiver's personal budget on their behalf to care-receiver's managing their own care support independently via a direct payment.

<sup>98</sup> These charges are commonly applied to telecare, community alarms and community meals services. In LA2 the first 4 weeks of residential respite care provision is subject to a flat rate charge of £106.40 per week (L2LAP1/L2LAP2).

<sup>99</sup> Only those in receipt of basic means-tested benefits only are not charged.

<sup>100</sup> £5 per hour (L2LAM2).

<sup>101</sup> One interviewee reported 'self-funders' in another local authority being charged just over £14 an hour for their carer break services, '.....[S]o to go out and meet a friend for coffee its going to cost £28....so how many carers are going to do that?' (L1TS1M).

risk-related dilemmas for carers. Several interviewees criticised these charging policies for forcing carers to choose between either potentially exacerbating their extended poverty risks by paying for services which would enable them to continue caring but which would require them to spend the 'nest egg which they have saved up for years....[which is] there in case anything terrible happens' (L1TS1M/NTSPR); or seeking to protect their future financial security by doing without carer support services but exacerbating their current welfare risks instead.

#### **6.4.2.2 Implicit and indirect treatment of income**

Income is also implicitly and indirectly used to determine statutory outputs across the care services and employment domains. This is due to some local authority policies and statutory regulations surreptitiously privatising some, or all, of the financial costs associated with particular care options which can contribute to inequalities forming across care relationships on account of their income status. For example, in LA2 although carers are not officially charged for carers services, the Resource Allocation Panel was noted to be 'sneakily' applying top up charges to carers' funding requests (L2TS1M1). This was illustrated using the case of local gym memberships which cost £600. The local authority would provide a maximum statutory contribution of £500 thereby requiring carers to contribute the remaining £100 if they want to access this type of carer break (L2TS1M2/L2TS1M1). Similarly in relation to care-receivers services, local authorities were noted to set a fixed personal budget amount for day care places (L1LAP2); and to only provide enough funding to cover the cost of purchasing a cheaper domiciliary care agency (L1LAP3/L1LAP1). So, if someone wants,

*'....something more than that that's where you are going to have to look at topping it up yourself' (L1LAM1).*

These indirect charging strategies may prevent less affluent care relationships from accessing particular types of support or restrict their choices to lower quality or lower frequency service options due to being unable to afford to pay these privatised charges. Meanwhile, in the employment domain, access to emergency care leave or flexible working is implicitly affected by an individual's income status due to both sets of regulations privatising the financial costs associated with reconciling work and care for employed carers. For flexible working requests often result in a reduction in contracted working hours, and employers only have a statutory duty to offer *unpaid* care leave. Consequently more affluent carers are more likely to activate these employment rights due to being cushioned by the additional financial resources at their disposal. Whereas low income carers may face increased dilemmas due to being unable to cover the privatised costs of temporarily

or permanently reducing their income. However, their inability to activate these rights could in turn exacerbate their time poverty and welfare risks.

### 6.4.3 Employment status of the carer

Figure 24 reveals the carer’s employment status to have significant implications for how the state treats their care-related risks across a number of policy domains and policy mechanisms. A carer’s employment status is often assigned by states on account of the type of cash benefit they are entitled to, and carers may be subject to unequal statutory protection by state policies and practitioners as a result. Moreover, carers sharing the same employment status may experience unequal treatment by different practitioners. In the employment and cash benefits domains in particular, this characteristic is not independently significant but is intersected with care and income based characteristics.

**Figure 24: Significance of the characteristic of employment status**

Characteristic	Cash Benefits	Care Services		Employment	
		Care-receiver (CR)	Carer (C)	JCP Support	Employment policies
Employment status of carer	Significant (CA/IS/JSA/WTC)	Less significant (practitioner variation)	Less significant (practitioner variation)	Significant	Less significant (FW only)

#### 6.4.3.1 Differential treatment of non-employed, unemployed and employed carers

The treatment of carers by the state in relation to participating in the labour market is prescribed by their income level and the level of care they provide. These characteristics determine which cash benefit carers can access which in turn confers upon them their employment status. In the JCP employment support domain receipt of Carers Allowance (CA) acts as a protective cash benefit by granting carers the status of **full-time non-employed carers**, and provides the evidence that they are engaged in a legitimate alternative activity to paid employment. All carers in receipt of CA are therefore not required to participate in the labour market but they remain entitled to access all available Jobcentre Plus (JCP) support if they choose (L2JCP1). However for less affluent carers who are in receipt of CA and IS, being in receipt of a means-tested benefit requires them to attend a ‘...mandatory [JCP] interview once every 3 years’ (L1JCP1). Failure to comply can result in benefit sanctions being applied (L2JCP1).



Meanwhile low income, non-employed, 'part-time' carers (e.g.CR3) who fall outside the CA catchment on account of the level of care they provide must claim Jobseeker's Allowance (JSA), and were consequently described by one interviewee as being 'between a rock and a hard place' (L2JCP1). This is because carers in receipt of this means-tested benefit are categorised as **unemployed workers** and face the same conditionality applied to all other recipients to enter paid employment as soon as possible. Consequently they must attend the JCP office fortnightly (BTSP1); actively seek work and demonstrate that this forms '.....a significant part of your day to day activities taking several hours a day' (L2JCP1); and formulate a Jobseeker's Agreement. The only concessions made for JSA recipients with caring responsibilities is that the regulations permit them to apply more 'generous' restrictions to their Jobseeker's Agreement than other unemployed claimants.<sup>102</sup> However, any claimant failing to comply with the terms of their Jobseeker's Agreement are subjected to benefit sanctions consisting of '.....a financial punishment which can be total removal of benefits, or paying of a reduced amount for varying lengths of time' (L2JCP1).

Carers who are in paid employment are primarily treated by the state as **workers** and consequently face a lack of statutory protection across each policy domain with managing the care-related risks associated with reconciling their work and caring roles. For the earnings restrictions placed on access to CA and the lack of recognition of working carers in the Working Tax Credits regulations<sup>103</sup> ensures that employed carers' poverty risks remain privatised. Meanwhile in the employment domain the regulations stipulate that employees must have been employed continuously by the same employer for at least 26 weeks prior to making a flexible working request (Directgov, 2012n). This presents a significant barrier to carers re-entering the labour market or changing jobs. Furthermore in the care services domain, local authorities have a duty when carrying out a carer assessment to consider the impact that the caring role might have on a carer's employment commitments or aspirations (Department of Health, 2001, 2010a; HM Government, 2004). However, in practice the extent to which practitioners and managers in resource allocation panels (RAP) take a carer's employment status into account is variable. Only some practitioners awarded higher eligibility bandings to employed carers (L1LAM3), and assessed the part-time employed carer (CR8a) to require additional replacement care services in the form of day care (L1LAP3) and domiciliary care 'because the carer is also trying to hold down a job' (L1LAP1). However, generally inadequate care packages and inappropriate service options were reported to be provided.

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<sup>102</sup> Carers can specify: the number of hours they are available to work as long as it is at least 16 hours per week and they still 'have a reasonable prospect of securing employment despite that restriction'; and can request 48 hours notice to attend a job interview; and one week's notice to commence a job (BDWPM2).

<sup>103</sup> Discussed in Section 7.3.2.

*'I don't think they [RAP] do take it into account because most of the people that they're saying can provide support at the weekends are working....So they're not getting a break because they're working all week and then they're spending the weekends caring...'* (L1LAP2);

*'.....the panel still prefer universal [day] services to be used' even though 'if the carer was going to.....work universal services would not give them enough time to do so'* (L1LAP1).

Overall this evidence reveals that existing statutory support systems do not adequately recognise employed carers or protect them from the financial, time poverty or welfare risks of combining work and care.

#### 6.4.4 Age of the carer

Figure 25 reveals how the characteristic of age ranges from being significant to insignificant across policy domains and practitioner decision-making. However, its significance is either subordinated to, or directly connected to, the characteristics of health and employment status, thereby making it a less influential characteristic in its own right. Even so, it contributes towards significant age-related inequalities emerging in the statutory entitlements of working-aged and pension-aged carers in the cash benefits domain.

**Figure 25: Significance of the characteristic of carers' age**

Characteristic	Cash Benefits	Care Services		Employment	
		Care-receiver (CR)	Carer (C)	JCP Support	Employment policies
Age of carer	Significant (AA/CA/means-tested benefits)	Less significant (Subordinate/practitioner variation)	Not significant	Not significant	Not significant

##### 6.4.4.1 Inconsistencies in the treatment of working-aged and pension-aged carers

In the cash benefits domain the state treats carers of working age and pension age unequally on account of their age and employment status. Working-aged carers remain the key beneficiaries of Carers Allowance despite the age-related restriction for accessing CA being removed in 2002.<sup>104</sup> Carers who are in receipt of a basic state pension (BSP) are only permitted to have an underlying, rather than an actual, entitlement to CA due to overlapping benefit rules. Consequently most pension-aged carers are implicitly excluded from receiving this care-related statutory financial

<sup>104</sup> Prior to the Regulatory Reform (Carer's Allowance) Order 2002 (HM Government, 2002) carers over the age of 65 were exempt from receiving CA.

protection<sup>105</sup> and must instead use their pension income to cover their care-related poverty risks. Even so, low income carers of pension age receive more generous state financial support overall than full-time carers of working age due to the age-related disparity which exists in relation to each age group's personal allowances.<sup>106</sup> This illustrates that the state does not fully recognise the poverty risks associated with the caring role for either age group. For the state only responds to the poverty risks associated with older carers' old age, treating them as **pensioners** first and foremost. Meanwhile full-time carers of working-age receive only marginally higher levels of financial protection than other unemployed individuals who have no caring responsibilities.<sup>107</sup>

In the care services domain inconsistencies emerged across practitioners as to whether they considered the age of the carer to be significant for determining the level of statutory support the caring dyad could access. Some interviewees stated that 'Age has got nothing to do with it....' (L1LAP2/L1LAM1/L2LAM2). Meanwhile where participants did consider age to be a significant characteristic, they had generally conflated old age with the increased likelihood of an individual being in poor health (L2LAM1/L2LAM2/L1LAM3).

*You often find that....by the time you get an older person with an older partner they've both got health frailties and you need to recognise that in the support package' (L2LAM1).*

Consequently some practitioners assessed care relationships containing older couples to need more day care than those containing working-aged carers (L1LAP3/L1LAM1). Even so, age remains a subordinate characteristic in this policy domain due to its significance being contingent upon poor health status.

#### **6.4.5 Health status of the caring dyad**

The characteristic of the health status of the caring dyad is less significant overall for determining the caring dyad's access to statutory support due to it being applied neither comprehensively nor consistently across policy domains and policy mechanisms. Figure 26 reveals how it forms a key feature of the eligibility criteria of only a few policy regulations and is a discretionary factor taken into account by only some practitioners.

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<sup>105</sup> They can only receive a CA payment if their BSP rate is lower than CA. Under those circumstances CA is only used to top up their BSP to the level of CA, with Pension Credit making their income up to their overarching personal allowance amount.

<sup>106</sup> The personal allowances of carers of pension age and working age are £175.30 and £103.60 per week respectively (Figures for 2012-2013).

<sup>107</sup> Whose personal allowance is £71 per week.

**Figure 26: Significance of the characteristic of health status of caring dyad**

Characteristic	Cash Benefits	Care Services		Employment	
		Care-receiver (CR)	Carer (C)	JCP Support	Employment policies
Health status of CR and /or carer	Less significant (Passported benefits only)	Less significant (practitioner variation)	Less significant (practitioner variation)	Significant	Less significant (TOIE only)

#### 6.4.5.1 Inconsistencies in the treatment of health status

In the employment and cash benefit domains, the health status of the care-receiver is used with varying degrees of specificity to determine the eligibility of both caring dyad members to certain elements of statutory support. The generic health status of the care-receiver is used to determine carers' access to time off in an emergency, which requires the 'dependent' person to be experiencing an illness or injury of a mental or physical nature (HM Government, 1999; Directgov, 2012o). Similarly, in order to access JCP support or apply care-related restrictions to Job Seeker's Agreements respectively, carers must either be caring for someone who is '....ill, frail, disabled or has mental health or substance misuse problems' (Department of Health, 2008, p. 19); or '....who...needs to be cared for because of their physical or mental condition' (BDWPM2). Meanwhile in the cash benefits domain the specific health condition of the care-receiver is only used explicitly to determine their access to one particular passported benefit.<sup>108</sup>

In the care services domain, inconsistencies emerge in the extent to which practitioner decision-making is affected by the health status of the caring dyad. For some practitioners, the care-receiver's specific health condition influenced their eligibility and statutory support decisions. For example, the duration of a care-receiver's domiciliary care visit was noted to,

*'depend very much on the person and their illness....You know if they've got rheumatoid arthritis or a respiratory disease you can't rush people' (L2LAP1/L2LAP2).*

Dementia diagnoses also consistently increased the level of statutory support practitioners assessed care-receivers to need. This contributed to low need Tier 3 care-receivers being considered eligible to access statutory support (L2LAP1); higher levels of day care being provided by local authority rather than universal service providers (L1LAP1); and the provision of meals via a domiciliary care service instead of a home meals service (L2LAP2/L2LAM2/L2LAM1). Meanwhile, a carer's poor physical or mental health could contribute to some practitioners enhancing their statutory response. This included part-time Tier 3 carers being granted access to a carer assessment (L2LAP1/L1LAP2);

<sup>108</sup> People with a 'severe mental impairment' can be discounted from council tax calculations (Directgov, 2012e).

being considered eligible to access statutory support (L1LAP2/L1LAP1/L1LAP3); with the level of respite care provided to the care-receiver also being noted to depend on ‘how stressed the carer is’ (L2LAP1/L2LAP2). Even so, not all practitioners took this characteristic into account, with one commenting that if the care-receiver ‘....doesn’t meet our criteria in the first place.....that’s what we will be going on’ (L2LAP1).

#### 6.4.6 Inter-relational characteristics of the caring dyad

The significance of the different inter-relational characteristics for determining the caring dyad’s access to statutory entitlements varies across policy domains and practitioner decision-making. Figure 27 reveals how the characteristics of relational status and living arrangements are used more comprehensively and consistently than gender and quality of relationship to determine entitlements. However, these characteristics are applied inconsistently across eligibility criteria and decision-making due to being used with both inclusionary and exclusionary intent. This inconsistent application can result in members of the caring dyad being simultaneously permitted and excluded from accessing different types of statutory support on account of exactly the same characteristic. The differential application of these inter-relational characteristics contributes to substantive differences emerging across the assessed statutory outputs of even similar care relationships.

**Figure 27: Significance of inter-relational characteristics**

Characteristic	Cash Benefits	Care Services		Employment	
		Care-receiver (CR)	Carer (C)	JCP Support	Employment policies
<b>Relational status/ Marital Status</b>	Less significant (CTB only) CA (indirect)	Less significant (practitioner variation)	Less significant (practitioner variation)	Significant	Significant
<b>Living arrangements</b>	Less significant (SDA/CTB only)	Less Significant (practitioner variation)	Less Significant (practitioner variation)	Significant	Significant
<b>Quality of care relationship</b>	Not significant	Less significant (practitioner variation)	Less significant (practitioner variation)	Not significant	Not significant
<b>Gender</b>	Not significant	Less significant (practitioner variation)	Not significant	Not significant	Not significant

##### 6.4.6.1 Inconsistencies in treatment of relational proximity, relational quality and gender

The relational status of the caring dyad is used in two contrasting ways across the eligibility criteria of different policy domains and policy mechanisms. In the employment domain it is used inclusively to categorise a wide selection of relationships as eligible to access statutory rights and support,

although individual policy mechanisms vary as to the relational proximity required to grant eligibility. For example the right to request flexible working<sup>109</sup> and the ability of carers to apply restrictions to their Jobseeker's Agreement<sup>110</sup> requires the care to be provided to close relatives. Whereas access to JCP support (Department of Health, 2008, p. 19) and the right to take time off in an emergency<sup>111</sup> utilise wider criteria which incorporate the care of friends, neighbours and more distant relations as well. Meanwhile a few of the policy mechanisms found in each policy domain explicitly prohibit particular relational groups from accessing statutory support, with closer relational proximity guaranteeing exclusion. Consequently carers who live with the person they care for are only eligible to access a Council Tax exemption if they are caring for someone other than their spouse or partner (Directgov, 2012f). In the JCP domain, funding for replacement care to enable a carer to attend a job interview or training cannot be used to pay relatives (L1JCP1). Similarly in the care services domain direct payment regulations stipulate that care-receivers 'may not normally' employ close family to provide their care.<sup>112</sup> Under exceptional circumstances these relational exemptions can be disregarded if the local authority considers it to be the only satisfactory way to meet an individual's care needs (Department of Health, 2003a). Even so, one local authority manager was reluctant to apply this disregard to 'very close relatives' and spouses due to the dilemmas they can face negotiating their existing personal relations within a more formalised care arrangement.

*'You have a big fall out with your mum, what do you do.... you are employed as her P[ersonal] A[ssistant], how does she get her next meal?' (L2LAM1).*

Meanwhile in the care services domain, practitioners varied in the extent to which they took the relational status and gendered configuration of the caring dyad into account when assessing what statutory support to provide. Some practitioners explicitly stated that gender did not affect their decision-making (L1LAP3/L2TS1M1). However, others considered cases involving married couples (L1LAP1/L2LAM1) and filial care relationships where sons care for their mothers to require more statutory support with managing personal care. However these decisions were not replicated in relation to daughters caring for their fathers (L2LAM1).

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<sup>109</sup> An employee's spouse, partner or civil partner; immediate or near relatives (including mother, father, and siblings, grandparents respectively), or someone who lives at the same address as the employee (HM Government, 2006a; Directgov, 2012n).

<sup>110</sup> '....[A] child or an elderly person or a person who needs to be cared for....and who is in the same household or a close relative\* (BDWPM2) \*(defined as a partner, parent, child or sibling) (Carers Direct 2012a).

<sup>111</sup> Covers cases where care needs to be arranged or provided for any other person who reasonably relies on them (HM Government, 1999).

<sup>112</sup> Including from a spouse or partner; a close relative that you live with; anyone who lives in the same household (Department of Health, 2003a; Directgov, 2012k).

*'I think the older person is likely to get more services if she has got a son. It's deemed to be better or OK for a women to give personal care to their mother than it would be for a son. Which shouldn't be the case but....Daughters seem more willing to do it, and sons, well they don't want to see their mum's naked, well daughters don't, but.....it's seen as.....infringing on the dignity of the older person for the son to do something where as it isn't for a daughter' (L1LAP2).*

*'....I think it's considered that men are more used to having women do that sort of care for them' (L1LAP2).*

For some practitioners their decision-making was also influenced by the emotional and relational aspects of the care relationship, 'You know the family issues and dynamics' (L2LAP2); how difficult or easy going the person they are caring for is, because that can have a real bearing' (L2LAP3). Moreover, some practitioners were mindful of the implications that the quality of the care relationship could have for the quality of care provided (L2LAP2),

*'Just because you are related to that person does not mean you've got a relationship which allows you to feel that you want to help them. If people are pressured into doing something they don't actually want to do....it can lead to abuse' (L1LAP1).*

#### **6.4.6.2 Inconsistencies in treatment of caring dyad living together or living apart**

The physical proximity of the caring dyad's living arrangements is used across policy domains and within practitioner decision-making in contrasting ways to determine the level of statutory protection the caring dyad can access. Living in the same household as the care-receiver is explicitly used to grant carers' access to a wide range of employment-related support including flexible working, taking time off in an emergency, and applying restrictions to their Job Seeker's Agreement. In the care-services domain although practitioner decision-making is significantly influenced by this characteristic, practitioners varied as to whether living together or living apart would enhance or reduce a care relationship's assessed level of support. Some practitioners awarded live-in carers higher eligibility bandings due to considering these living arrangements to produce additional stress (L1LAP1), while others took into account the considerable stress faced by carers living separately from the care-receiver.

*'...[T]ravelling to and from even if they live locally....and you know the stress of....having to manage and juggle two separate households...so I think there's potential here for them to have standard needs or enhanced....' (L1LAM3).*

Other practitioners assessed care-receivers living separately from their carer to be eligible to access domestic care support which they would not provide if the same individuals lived together.

*'[I]f the [carer] is physically there....you wouldn't put a meal call in,.....if they weren't though you wouldn't expect a family member to go down....to do that every day' (L2LAP2);*

*'.....[Y]ou must look at why you are providing services when there are....able-bodied people in the household. So it would be a different scenario to somebody who was living alone where those people were coming in from outside and travelling' (L3LAP1).*

Where living together was more likely to result in the caring dyad receiving more support was in relation to carer break services (L1LAP3).

*'....[I]f the cared for person has....dementia....he just says the same thing over and over....Somebody living with the person day in, day out is possibly going to need more....of a break' (L1LAM3).*

Even among care-receivers with equivalent care needs, some practitioners considered those care relationships where members live together to have '....more scope for a sitting service' (L2LAP2/L2LAP1/L1LAP1/L1LAM1). However other practitioners assessed all eligible care relationships to be able to access carer break services regardless of their living arrangements (L1LAP2/L1LAP3/L1LAM3).

#### **6.4.6.3 Inconsistencies in the treatment of single and married carers**

The marital status of carers is treated inconsistently across policy domains. In the care services domain, only specialist carer assessors took into account the needs of single and married carers when assessing their need for sitting services in order to reduce the negative impact of caring on their wider relationship needs.

*'If they are single and they wanted to pursue some kind of a social life so that they could meet somebody....we could ...maybe get some evening sats put in' (L2TS1M1);*

*'....a husband and wife caring for mother.....can have an impact on their relationship....because they don't get a chance to spend any time [together]....' (L1LAM3).*

Meanwhile in the cash benefits domain, due to the CA regulations taking into account carers' own direct income but not their partners' earnings (Child Poverty Action Group, 2012), non-working married or co-habiting carers living in potentially more affluent households (CR8b) could find themselves eligible to access this statutory financial protection while potentially low income, single, working carers (CR8a) are excluded. This is despite the latter experiencing more significant poverty risks on account of their marital status due to having no access to any spousal financial protection.



## **6.5 Overarching significance of characteristics across policy domains**

This chapter reveals a central facet of the complexity of the care policy system by exposing the lack of overarching consistency in the treatment and significance of different characteristics across policy domains, individual policy mechanisms, localities, practitioners, and caring dyad members, for determining access to statutory support. By consolidating all of the characteristics into one chart (see Figure 28) the patchwork nature of each characteristic's significance is revealed. Inconsistency emerges along both the vertical and horizontal axes. For there are no clear patterns in relation to the configuration of characteristics which are required for accessing statutory support across each policy domain. Moreover, no individual characteristic is assessed to be significant across every policy domain. Instead only a loose hierarchy of characteristics emerges from this analysis. The most significant characteristics are the level and type of care provided by the carer, followed by the level and type of care need required by the care-receiver due in part to the contingent nature of a substantial number of carers' entitlements. These therefore constitute key characteristics due to being explicitly used by the state as key criteria for including or excluding the caring dyad from access to statutory support and protection across at least two domains. Other significant characteristics include the carer's employment status and the living arrangements and relational status of the caring dyad, particularly as the two inter-relational characteristics have the ability to over-ride other key characteristics, such as the level of care provided, for determining access to statutory support. Meanwhile income, age of the carer, health status of the caring dyad, impact of caring, gender, and quality of the care relationship, constitute less significant characteristics due to each of them lacking comprehensive representation and utilisation across all policy domains. Even so within certain policy mechanisms, characteristics such as income, age and the impact of caring, remain highly significant, and can in certain cases take precedence over other key characteristics, for determining eligibility.

**Figure 28: Evaluating the overall significance of characteristics across policy domains**

Characteristic	Cash Benefits	Care Services		Employment	
		Care-receiver (CR)	Carer (C)	JCP Support	Employment policies
Level/type of need of CR	Significant (AA,CA,CC, IS)	Significant	Less significant (practitioner variation)	Less significant (indirect)	Less significant (implicit)
Level/type of care provision by carer	Significant (CA,CC, IS/JSA)	Less significant (practitioner variation)	Significant	Significant	Less significant (implicit)
Impact of caring role	Less significant (IS only)	Less significant (practitioner variation)	Significant	Less significant (practitioner variation)	Not significant
Income of CR	Less Significant (Means-tested benefits only)	Significant	Not significant	Not significant	Not significant
Income of Carer	Significant (CA, IS/JSA, WTC)	Not significant	Less significant (LA variation)	Not significant	Less significant (implicit)
Employment status of carer	Significant (CA/IS/JSA/WTC)	Less significant (practitioner variation)	Less significant (practitioner variation)	Significant	Less significant (FW only)
Age of carer	Significant (AA/CA/means-tested benefits)	Less significant (Subordinate/practitioner variation)	Not significant	Not significant	Not significant
Health status of CR and /or carer	Less significant (Passported benefits only)	Less significant (practitioner variation)	Less significant (practitioner variation)	Significant	Less significant (TOIE only)
Relational status/ Marital Status/	Less significant (CTB only) CA (indirect)	Less significant (practitioner variation)	Less significant (practitioner variation)	Significant	Significant
Living arrangements	Less significant (SDA/CTB only)	Less Significant (practitioner variation)	Less Significant (practitioner variation)	Significant	Significant
Quality of care relationship	Not significant	Less significant (practitioner variation)	Less significant (practitioner variation)	Not significant	Not significant
Gender	Not significant	Less significant (practitioner variation)	Not significant	Not significant	Not significant

This analysis exposes how determining eligibility to access statutory support is characterised by significant complexity, inconsistency and unpredictability which can have major implications for care-receivers and care-givers. A key effect of this complex and inconsistent treatment of characteristics is that it creates substantive uncertainty for those people engaged in the provision or receipt of care because there is no single set of characteristics which guarantees automatic entitlement across every domain. Moreover, the state's inconsistent recognition and treatment of different types of risk-bearers is revealed to significantly and unfairly disadvantage certain groups by excluding them from accessing statutory protection on account of factors over which they often

have little or no control. This nuanced analysis also helps to reveal how inequalities in the statutory entitlements of care relationships can emerge in a number of ways. Firstly, individual members of the caring dyad can themselves face inconsistent access to statutory entitlements because the weighting of a particular characteristic's significance varies across individual policy mechanisms; and specific characteristics may be utilised in contradictory ways to either support the inclusion or exclusion of the same individual from different statutory entitlements. Furthermore access to some statutory entitlements may be dependent upon complex configurations of characteristics being present in an individual's circumstances, meanwhile other characteristics may not be recognised by the state. This can contribute to individuals receiving statutory support in relation to some of the care-related risks they face while their other risks remain unprotected and privatised. Secondly, the members of the caring dyad may experience unequal statutory protection to one another because particular characteristics are treated in contradictory ways by statutory regulations. So while one member's care-related risks may be socialised, the other's may remain privatised which has the potential to create inter-dyadic conflicts and dilemmas between carers and care-receivers. Thirdly, the levels of statutory protection care relationships can access can be significantly affected by discretionary decision-making due to agencies and practitioners determining the significance of particular characteristics. Characteristics such as the impact of caring and personalisation approaches which demand subjective judgements to be made, contribute to exacerbating inconsistencies across the statutory support outputs of care relationships. All these findings ultimately expose a core component of the institutional complexity pervading the care policy system, which contribute to the unequal treatment and protection of carers, care-receivers and care relationships by the state.

## **6.6 Conclusion**

The findings presented in this chapter, revealing the state to treat the care-related risks of different types of carers and care relationships inconsistently, are the product of the state only partially recognising informal care as a social risk. By analysing the eligibility criteria of care-related policies, practitioner decision-making and the statutory support outputs of the care relationship types, this chapter exposes the state's incomplete acknowledgement, recognition and treatment of informal care as a social risk. It highlights how the state's recognition and treatment of the care-related risks associated with informal care is characterised by significant variability and inconsistency both within each policy domain as well as across policy domains. It reveals the definition of what constitutes care as well as individual's characteristics to be subject to inconsistent treatment by policy regulations and practitioners across policy mechanisms. This gives rise to unequal outcomes in the

level of statutory protection provided by the state to different types of carers, care-receivers and care relationships. For only certain types of individuals with caring commitments with very specific configurations of characteristics are formally identified as carers and recognised as facing care-related risks which require the protection of the state. The specific group that can be identified within this category are non-working, full-time, working-aged carers. Even so the extent to which the state can be said to adequately protect even this recognised group of carers against the care-related risks they face can be disputed on account of the inadequate levels of statutory support that are available. Meanwhile the care-related risks of other groups of carers, including part-time carers, older carers and employed carers, remain either unrecognised or only partially recognised by the state. These excluded carers may be provided with statutory support and protection in relation to other recognised social risks which affect them, such as being unemployed, over retirement age or a low income worker, however their care-related risks remain fully or partially privatised.

In order to understand the existence of the complexity, unpredictability and inequality revealed in this chapter, Chapter 7 will turn to examine the institutional structures and processes contained within the care policy environment with a view to helping to explain these policy effects. Thereafter Chapter 8 will examine the negotiations that take place within the policy environment which can add to the complexity and unpredictability of the caring dyad successfully navigating through the institutional system to access the statutory support that is available.

## **Chapter 7: Analysing institutional structures and processes in the care policy environment**

### **7.1 Introduction**

In Chapter 6 the focus was on revealing how members of the caring dyad are subject to unpredictable and inconsistent treatment by state regulations and practitioners due to the construction and interpretation of eligibility criteria. This variability was revealed to produce unequal access to statutory support and protection across care relationships. A key focus of this chapter is on undertaking a macro level analysis of the institutional structures and processes within each policy domain which contribute towards producing these policy effects. Analysing the construction of these institutional mechanisms can help to reveal how they shape the rights and entitlements of the members of the caring dyad; and how they can act as barriers to the caring dyad accessing adequate statutory protection from the care-related risks they face. The other key purpose of this chapter is to reveal the overarching trends in the treatment of informal carers and informal care across state policies, processes and policy domains. Examining the overarching treatment and positioning of informal carers within the care policy environment will reinforce the ability of this thesis to reveal the extent to which the state recognises and treats informal care as a social risk.

This chapter analyses the structure of the care policy environment in order to expose the complexity and fragmentation of the overarching policy terrain through which the caring dyad must navigate to access their statutory entitlements. The segregated nature of the individual policy silos is revealed to undermine the formation of cohesive policy interfaces and integrated agency responses thereby contributing to informal carers' needs and risks remaining unmet and unprotected. The systemic complexity is also exacerbated by the high levels of organisational and practitioner discretion permitted by the legislative framework which contributes towards territorial inequalities in statutory support outputs emerging across individuals according to where they live and work. Both factors contribute to a lack of transparency and predictability in the statutory protection provided across the care policy environment. This chapter also analyses the institutional processes contained within the care policy environment in order to expose the key trends in the overarching treatment of carers and informal care by the state. These include the derived nature of informal carers' entitlements which are often contingent upon the care-receiver's needs and statutory entitlements; the statutory weakness of the legislative provisions pertaining to informal carers; and institutional processes and

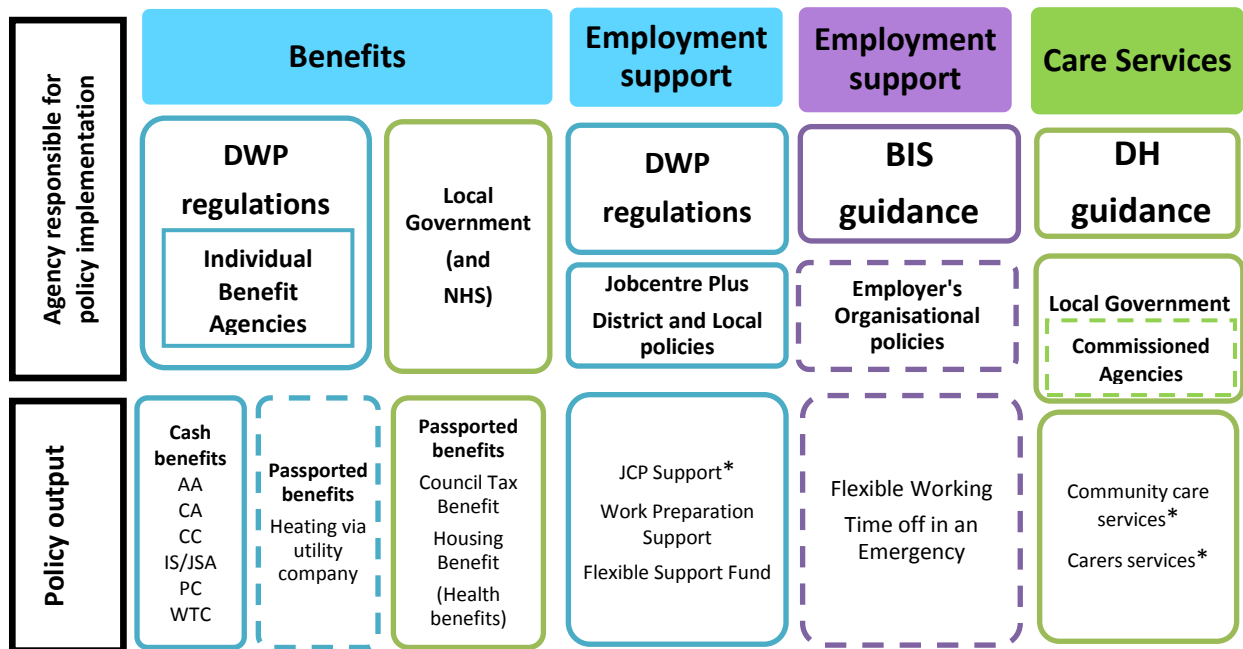
statutory provision being designed and administered to meet the needs of other groups of beneficiaries rather than informal carers. All of these trends can leave informal carers' needs and risks inadequately protected. The way in which institutional processes in the care services domain treat the inter-relational nature of care is also examined. This reveals that when the caring dyad is treated in a disaggregated way it can undermine the provision of holistic statutory protection and have negative implications for the overarching wellbeing of care relationships.

This chapter is structured as follows. Section 7.2 maps out the overarching policy terrain in order to fully reveal the structural complexity and fragmentation of the policy environment. Sections 7.3, 7.4 and 7.5 analyse the institutional processes contained within each of the policy domains in turn including: cash benefits; employment which incorporates JCP employment support and in work employment support systems; and care services. In the final section the extent to which the fragmentation of the overarching policy terrain is exacerbated by territorial, organisational and practitioner variations is assessed. Section 7.6 explores the implications of this systemic fragmentation from the perspective of potential beneficiaries to reveal how it undermines the provision of holistic and integrated statutory responses from being realised.

## **7.2 The complex structure of the overarching policy environment**

As discussed in previous chapters, a central contribution this thesis makes is its examination of the range of statutory entitlements available to the caring dyad across three key policy domains. This broad analytical approach is essential for analysing the extent to which the state protects different types of carers and care-receivers against the range of care-related poverty and welfare risks that they may face. Figure 29 maps out the overarching structure of the policy environment within which the statutory protection available to care relationships is situated.

Figure 29: The fragmentation of the overarching policy environment <sup>1</sup>



**Key to Figure 29**

- Solid line in any colour denotes central or local government agency responsibility:
- Blue: Department of Work and Pensions (DWP) domain;
- Green: Department of Health domain with devolved responsibility to Local Authorities;
- Purple: Department for Business, Innovation and Skills (BIS) domain
- - - Dashed line (any colour) denotes statutory responsibilities and operationalisation of policies devolved to external agencies and organisations

*Note:*

<sup>1</sup> Even though a substantial amount of JCP support (\*), community care and carer services (\*) are provided by external agencies, the statutory bodies of JCP and local authorities retain control over the type and level of support that is provided to carers and care-receivers. These policy output boxes are therefore depicted with a solid line to denote a statutory responsibility.

Figure 29 exposes the complexity and fragmentation of the care policy system. It reveals how each policy domain operates as a separate silo, falling under the statutory responsibility of different government departments to manage. These departments have overarching responsibility for ensuring the relevant statutory regulations are implemented. However, within each policy domain further fragmentation can occur due to individual policy mechanisms being operationalised by a diverse range of organisations and agencies. For example while all cash benefits fall under the broad remit of the DWP, each benefit is managed at a sub-departmental level by designated benefit

units.<sup>113</sup> Systemic fragmentation is exacerbated further in the case of care services and employment support. Care services are categorised as a local government responsibility and devolved to individual local authorities to manage who are permitted considerable discretion in the operationalisation of statutory regulations. Meanwhile, DWP responsibilities for providing support to individuals to re-enter employment are delegated to the Jobcentre Plus (JCP) agency at a district and local level. Non-governmental organisations may also be involved in the delivery of statutory support. For example local authorities may commission non-statutory organisations to undertake certain statutory functions or provide care services; the provision of passported benefits such as heating subsidies is undertaken by individual utilities companies; and the implementation of employment legislation is administered by individual organisations. This can result in a proliferation of policy outputs due to each organisation devising their own interpretation of the statutory regulations and varying in the degree of support provided to carers. The extent to which these diversifying effects create territorial and organisational inequalities in the statutory outputs of individuals on account of where they live and work, and the implications of the segregated nature of the overarching policy environment for the provision of support to individuals, will be explored in more detail in Section 7.6.

This chapter will first explore the institutional processes contained within the cash benefits, employment and care services domains in turn in order to reveal the overarching trends in the treatment of informal carers and informal care by the state. The term ‘institutional process’ refers to the administrative procedures through which individuals access statutory support. These processes, which assess eligibility and determine access to statutory funding and support, may either operate at the level of the overarching policy domain or at the level of individual policy mechanisms. As revealed in Chapter 6, the construction and operationalisation of these institutional processes can be influenced by the legislation and government regulations underpinning a particular policy mechanism; the policies constructed by the implementing agency in order to operationalise the legislative framework; and the decision-making of practitioners and managers charged with administering the institutional process. All of these elements will be taken into account in this analysis.

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<sup>113</sup> Carer’s Allowance (CA) is managed by the Carer’s Allowance Unit; Attendance Allowance (AA) is managed by the Disability Benefits Unit; means-tested benefits for people of working age including Income Support (IS) and Jobseeker’s Allowance (JSA) are administered by Jobcentre Plus; and Pension Credit is managed by the Pension Service.



## 7.3 Cash benefits domain

The analysis of the institutional processes contained within the cash benefits domain exposes a number of key findings pertaining to the treatment of informal care and informal carers by the state which subsequently emerge as patterns which are replicated across other domains. Firstly, the contingent nature of carers' statutory entitlements on the care-receiver's own entitlements is revealed more clearly here than in any other domain. Secondly, carers' entitlements are exposed as being weakly embedded within this policy domain in a number of ways. In addition to having only derived rights to any benefit entitlements, certain types of carer receive no statutory protection in relation to their care-related poverty risks. This is due to institutional absences existing, whereby certain benefit mechanisms make no provision for allowing the care-related needs and risks of carers to be recognised or compensated. Informal care is also found to be treated in the cash benefits domain anomalously to other types of care, and subordinately to other types of social risk. Altogether these findings highlight the peripheral positioning of informal care within the wider benefits system.

### 7.3.1 Carers' derived rights to care-related cash benefits

This analysis reveals that carers only ever have a derived right to cash benefits which offer them protection against the care-related poverty risks they face, they do not have a fundamental entitlement in their own right. To illustrate this point Figures 30 and 31 reveal how every care-related benefit and associated personal allowance premium for pension-aged and working-aged carers respectively, is contingent upon the *care-receiver* having an initial entitlement to Attendance Allowance (AA). Due to its integral importance for carers accessing statutory financial protection, one interviewee described this particular benefit as a 'building block' noting,

*'.....the first thing you look at with older people is AA.....and then you look at how you manipulate all the other benefits as a result of that really. So it's kind of all or nothing.'* (BTSP1)

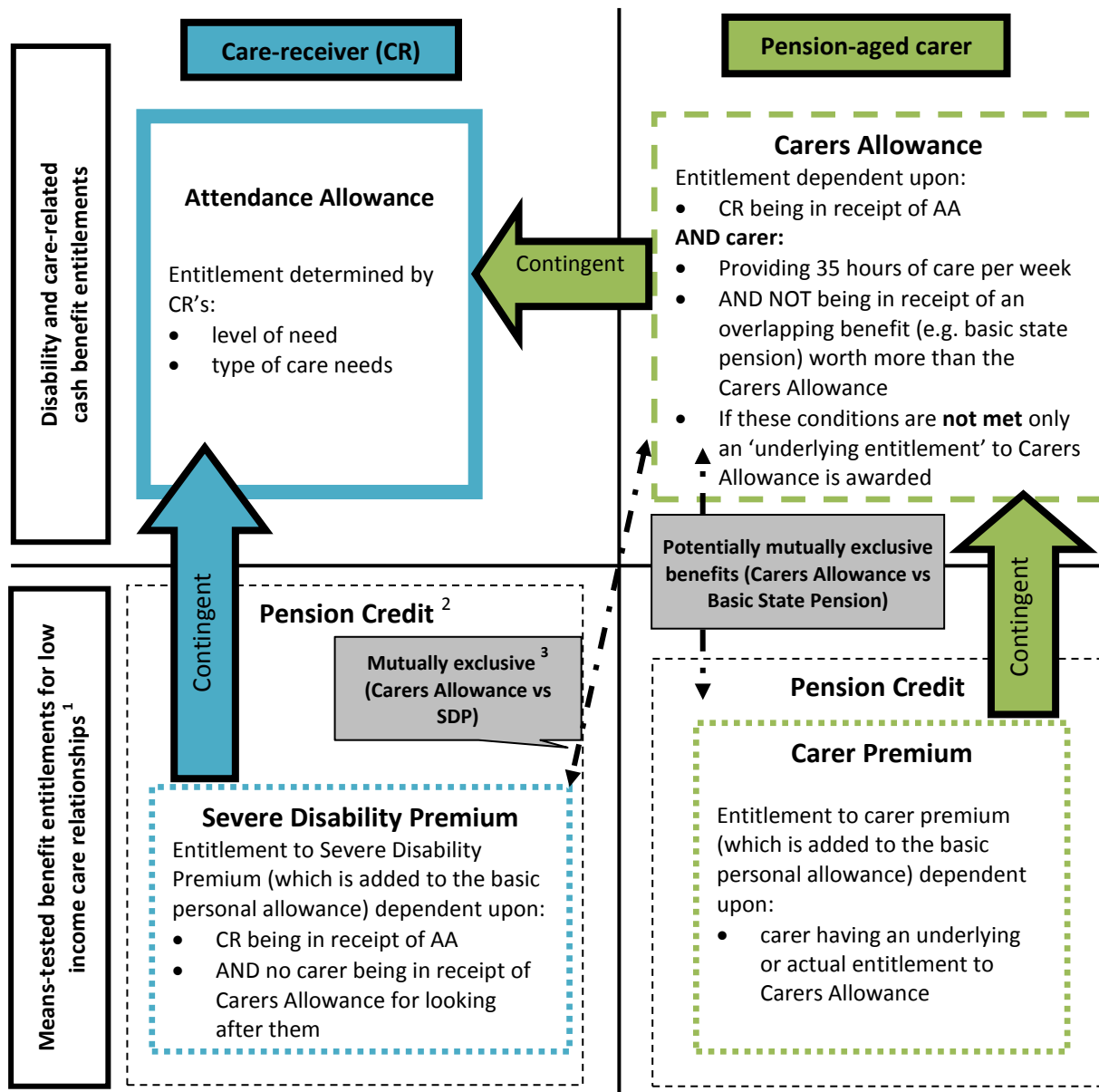
For example, a carer's ability to access the current and extended financial protection that Carers Allowance can provide hinges upon the person they care for being in receipt of AA. The care-receiver's receipt of AA must be formally stipulated in the carer's own benefit claim in order to confirm that they are caring for someone who is categorised by the state as severely disabled (Child Poverty Action Group, 2012). The derived nature of carers' rights to CA is also augmented by two further factors. The Carers Allowance claim form requires the care-receiver to confirm that they are aware that their carer is making a claim for Carers Allowance; and that their carer is 'caring for them for at least 35 hours a week' (Directgov, 2012g). Without this confirmation the DWP could refuse

the carer's claim (Child Poverty Action Group, 2012). Meanwhile access to the Carers Credits scheme,<sup>114</sup> Income Support (Department for Work and Pensions, 2012, para. 20116), and council tax exemptions on account of having caring responsibilities, are also contingent upon the carer-receiver being in receipt of a disability benefit such as AA. Consequently, it is the care-receiver's level of need which remains the critical criteria for the carer accessing statutory protection in their own right against the care-related poverty risks they face, while their own characteristics play a secondary role. The derived nature of all carers' cash benefit entitlements reveals how their rights to statutory financial protection are weakly embedded within the cash benefit system.

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<sup>114</sup> In situations where the care-receiver refuses to claim, or is not in receipt of, the applicable disability benefits the regulations permit Carer's Credits to still be awarded but only if a Care Certificate is supplied (Carers Direct, 2010). This certificate is signed by a health or social care professional to confirm that the care-receiver needs the amount of care specified by the carer (Department for Work and Pensions, 2010).

Figure 30: Institutional processes for pension-aged carers accessing care-related cash benefits



**Key to Figure 30 and 31**

- Solid coloured line denotes a key disability or care-related benefit entitlement
- ..... Dotted coloured line denotes a subsidiary entitlement dependent upon a key benefit
- - - Dashed coloured line denotes a superficial entitlement which does not provide a cash payment
- - - Black dashed line denotes a means-tested benefit entitlement not connected to disability or caring
- . - . - . Alternate black dashed and dotted line with attached grey text box denotes mutually exclusive benefits

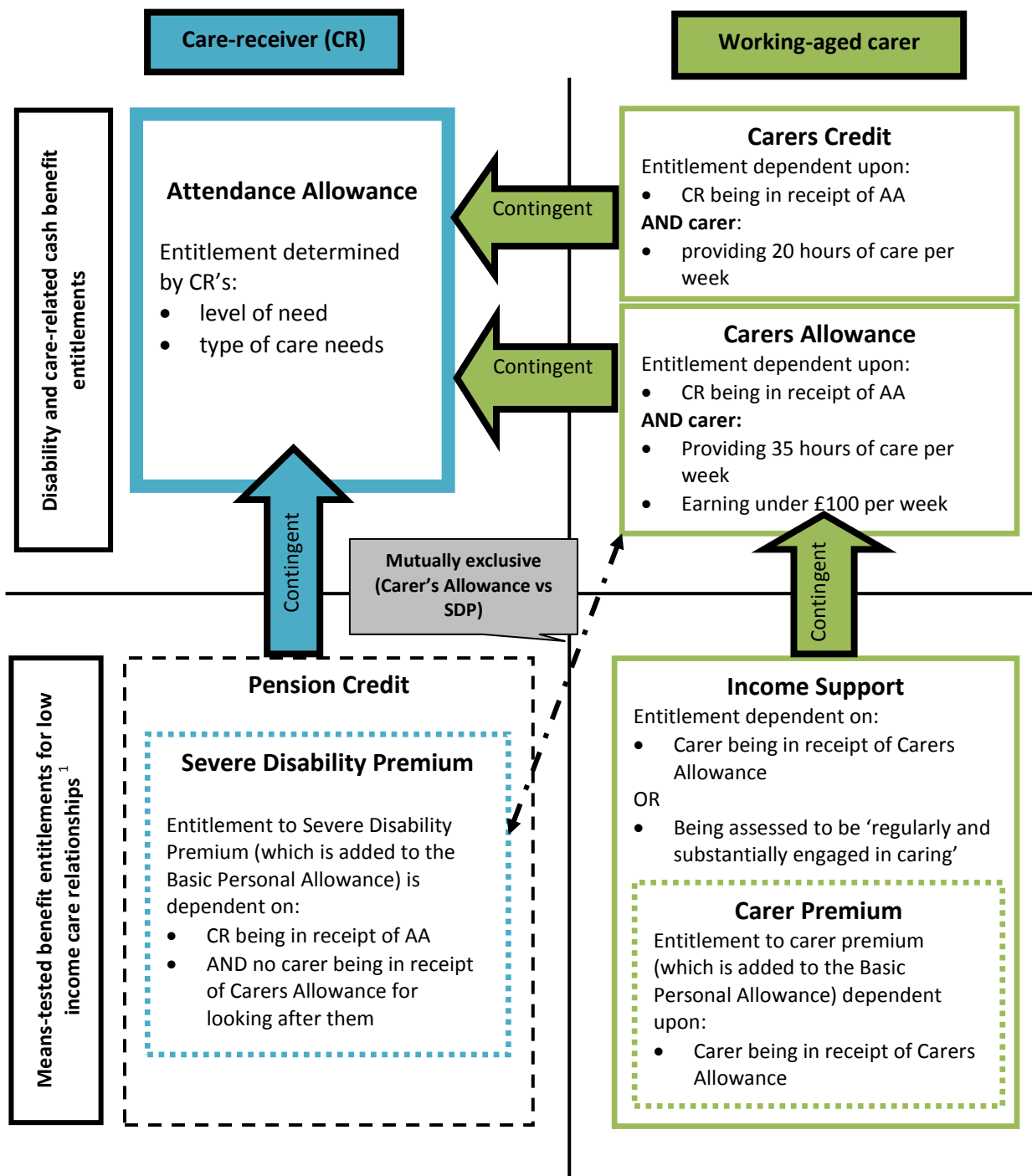
*Note:*

<sup>1</sup> To access means-tested benefits: an individual of pension age must have an income of less than the personal allowance (£142.70), there is no upper savings limit but tariff income applies to savings over £10,000 (Figures for 2012-2013).

<sup>2</sup> Pension Credit is paid as a top up to Basic State Pension (BSP) where an individual's BSP rate together with any additional income is less than an individual's Basic Personal Allowance amount.

<sup>3</sup> The implications of certain benefit mechanisms being designed to be mutually exclusive which can lead to inter-dyadic conflict is discussed in Chapter 8.

Figure 31: Institutional processes for working-aged carers accessing care-related cash benefits



Note:

<sup>1</sup> To access means-tested benefits: a person of working age (over 25) must have an income less than the personal allowance (£71) and under £16,000 in savings (Figures for 2012-2013).

### **7.3.2 Institutional absences and anomalies and the marginalised position of informal carers**

The marginalised position of informal care and carers within this domain is also illustrated by the existence of institutional absences and anomalies. Two key forms of statutory financial protection, Jobseeker's Allowance (JSA) and Working Tax Credits (WTC), which working-aged carers may require if experiencing unemployment or working poverty respectively, do not feature in Figure 31. This is because neither statutory provision contains any regulatory mechanisms which formally recognise informal carers. Consequently, carers in receipt of JSA receive the same level of financial protection as all other unemployed beneficiaries. Moreover, less affluent informal carers who participate in the labour market are treated in the same way as all other low income workers in only being able to access WTCs if they are working at least 30 hours per week. Furthermore, both sets of informal carers remain excluded from accessing Carers Allowance either on account of the level of care they provide or the amount of income they earn respectively. This evidence reveals that these carers are not recognised by the cash benefits system, and consequently their care-related poverty risks are left unprotected by the state and remain privatised.

The state is also revealed to treat informal carers anomalously to other types of carer in relation to a number of benefit mechanisms. For example, the poverty risks faced by low income carers engaged in the labour market are treated iniquitously by the WTC regulations depending on the type of person they care for. So while the care-related poverty risks faced by informal carers are ignored, the regulations both acknowledge and seek to protect working parents against the poverty risks which they face. For parents with dependent children are eligible to access WTC if they work 16 hours or more per week, with this entitlement also providing them with access to additional passported benefits, including help with health and heating costs and financial support with child care costs (Carers Direct, 2011j; Child Poverty Action Group, 2012; Directgov, 2012j). This unequal treatment occurs despite both groups of working carers experiencing similar care-related poverty risks and time constraints. Similarly, while the activity of caring for adults does not constitute a criterion for accessing a Warm Home Discount (WHD) from any energy providers, having caring responsibilities for young children does. This evidence reiterates the marginalised position of informal care within the overarching cash benefits system.<sup>115</sup>

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<sup>115</sup> It is worth noting here that similar unequal treatment occurs in the JCP domain where informal carers are only entitled to financial support with replacement care costs while looking for work, while lone parents can access funding for upfront payments to child care providers to enable them start work and in work emergency payments for replacement care (L2JCP1/L1JCP1).

Even where the benefit regulations do enable informal carers to be recognised, their care-related risks may continue to remain marginalised and unprotected. This is due to particular institutional processes being designed to prioritise the protection of certain social risks over care-related risks. For example, Figure 30 reveals how pension-aged carers are subject to mutually exclusive benefit regulations. Overlapping benefit rules stipulate that individuals cannot receive two earnings replacement benefits concurrently.<sup>116</sup> Where a dual entitlement exists the regulations require a contributory benefit, such as the Basic State Pension, to be paid in preference to a non-contributory benefit, such as Carers Allowance (Carers UK, 2012a; Carers Direct, 2012b). The CA regulations do contain an ‘underlying entitlement’ mechanism which enables the state to still recognise pensioners as carers. However, this only permits a symbolic acknowledgement of their caring role by the state whereby ‘they have an entitlement but receive no payment’ (BDWPM1). Consequently, this leaves their care-related poverty risks unprotected while their old age poverty risks are prioritised by the state.<sup>117</sup>

## 7.4 Employment domain

Analysing the institutional processes contained within the employment domain, both in relation to the statutory support available from Jobcentre Plus (JCP) and in the realm of paid employment, reveals how the treatment of informal carers by the state replicates some of the key themes emerging from the analysis of the cash benefits domain. Firstly, carers are found to occupy a peripheral position within this domain due to the statutory regulations and support being aimed at meeting the needs of broader groups of unemployed and employed workers. Consequently carers’ needs are either only partially met or ignored by the generic support and protection that is provided. Secondly, carers’ rights are weakly embedded in this domain both in relation to the strength of working carers’ legislative rights to statutory support in employment, and the treatment of non-employed carers in the JCP domain remaining influenced by the care-receiver’s entitlements. These findings explain why many of the care-related risks faced by carers remain privatised rather than socialised.

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<sup>116</sup> Earning replacement benefits are provided by the state and are intended to compensate those individuals who are unable to work on account of them experiencing specific contingencies such as unemployment, incapacity, and caring (Child Poverty Action Group, 2012; Carers Direct, 2012b).

<sup>117</sup> For low income carers in receipt of Guarantee Pension Credit (GPC) this underlying entitlement to CA can serve a more instrumental purpose by providing them with an entitlement to a carer’s premium which increases their GPC payment by £32.60 per week. However, this care based payment would remain hidden within their means-tested benefits rather than being explicitly acknowledged through a CA payment.

## 7.4 Part A: Jobcentre Plus employment support

### 7.4.1 Carers' derived rights to Jobcentre Plus support

Figure 32<sup>118</sup> illustrates how the care-receiver's disability benefit entitlement has an extended influence over how informal carers are treated by the state in the JCP domain. The level of compulsion carers are under to access JCP support and enter the labour market,<sup>119</sup> and the type and level of JCP support they can access, is determined by their specific benefit entitlement which is ultimately contingent upon whether or not the person they provide care to has an entitlement to Attendance Allowance. The regulations permit carers in receipt of CA, IS and JSA to receive JCP services and funding due to the expansive definition used within the JCP eligibility criteria.<sup>120</sup> However, practitioner decision-making about the type and level of JCP support carers can access is significantly influenced by the carer's specific benefit entitlement and its associated meaning regarding their proximity to the labour market. Whether a carer is in receipt of IS or JSA is revealed to affect the type of training course practitioners would permit them to attend; and their access to replacement care funding. Consequently carers in receipt of JSA are more likely to be considered eligible to receive replacement care funding but face more restricted training options. Whereas one practitioner applied greater leniency to the type of courses carers in receipt of IS could access, allowing recreational courses such as painting to be undertaken in lieu of more job focused training courses on account of the wellbeing benefits this could bring.

*'It's a....way to get back into the learning.....', it can 'build their confidence....because a lot of them haven't been doing any work or training for a number of years', '....they build friendships.....sometimes a lot of them have withdrawn from their friends because of the caring' (L1JCP1).*

However, another practitioner excluded carers from accessing statutory funding for replacement care to enable them to attend this type of course.

*'.....I might have difficulty with that. Because that course is not going to get them into work and in order to pay for care I would have to be able to satisfy my management stream that this job [sic]<sup>121</sup> could get them into work' (L2JCP1).*

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<sup>118</sup> Figure 32 illustrates the institutional processes used by the JCP offices in my two research sites. Other JCP localities are likely to follow a similar overarching framework but local policies and support outputs may vary.

<sup>119</sup> See Figure 32 Stage 1a. This was discussed in Section 6.4.3.1.

<sup>120</sup> See Figure 32 Stage 1b.

<sup>121</sup> Course

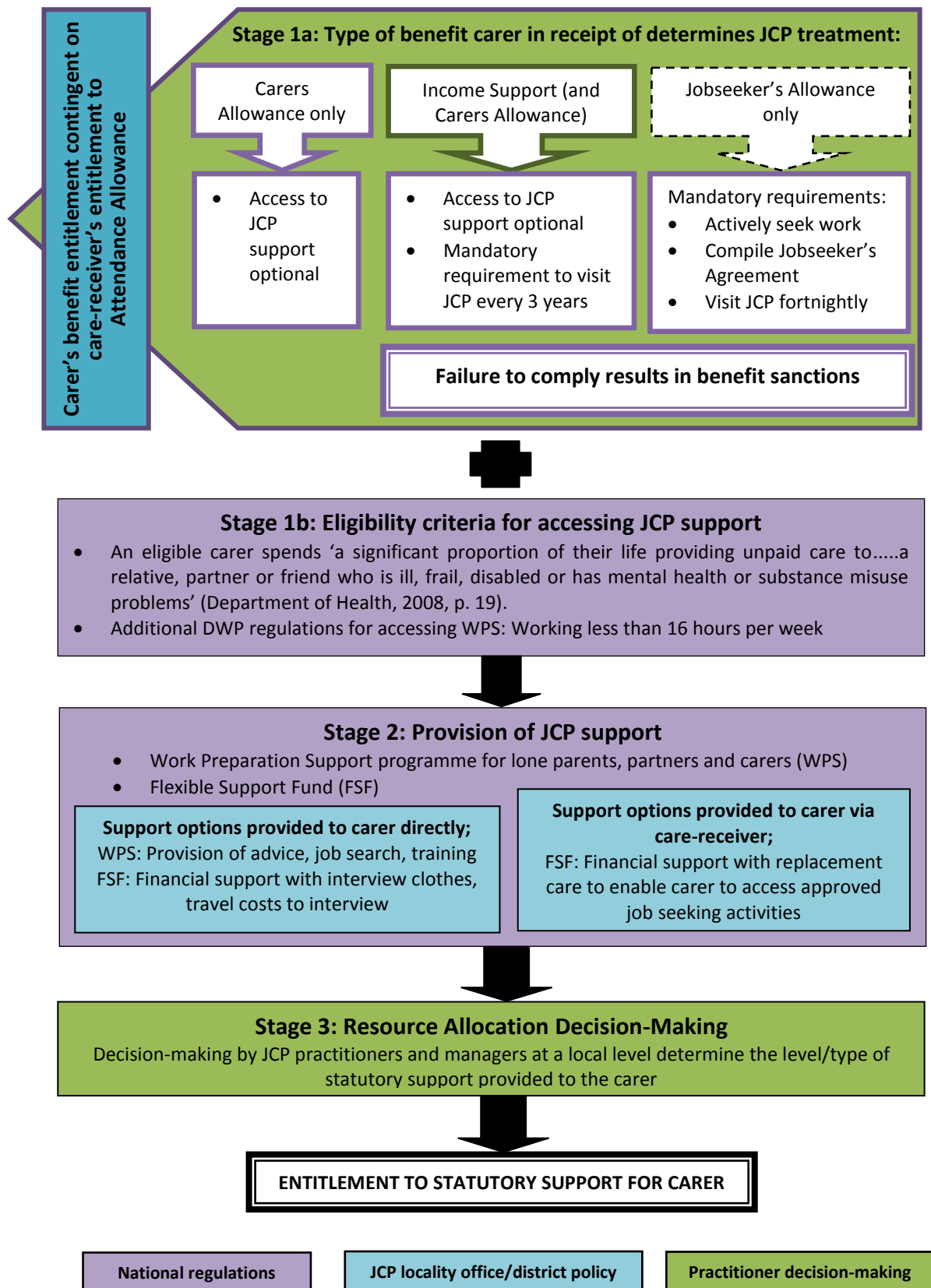
Moreover, further education colleges who provide back-to-work training in L2 were also found to treat JSA and IS beneficiaries unequally. JSA recipients could access the training courses free of charge, whereas IS recipients,

*'.....have to pay an upfront commitment payment I call it, its £75, which if they finish the course successfully they get back' (L2JCP1).*

This policy is intended to prioritise course access to those individuals 'who are closest to the job market' (L2JCP1). However, it has the potential to increase the financial risks of 'full-time' carers who are more likely to experience disruption to their course attendance due to their enhanced caring responsibilities.



Figure 32: Institutional process for carers accessing statutory support from Jobcentre Plus



#### **7.4.2 Marginalised position of carers within Jobcentre Plus support systems**

In the JCP domain the marginalised position of carers is revealed at both a strategic and operational level in relation to the diminution of specialist support available to carers. At a strategic level, previously New Labour had implemented a Care Partnership Manager role across JCP districts to specifically improve the employment support provided to carers. The role involved supporting JCP personal advisors in their work with carers; working to develop replacement care services; and building and maintaining partnerships with local authorities, health service, private and third sector (L2JCM1). However, in 2010 this specialist remit was absorbed into a more generic Partnership Manager role designed to cover a much wider range of government agendas.<sup>122</sup> This reduced focus on carers can be exacerbated by the level of discretion district managers are permitted in deciding 'how this function is delivered' (L2JCM1). Consequently, 'the amount of time Partnership Managers devote to carers' issues varies from one district to another' (BDWPM2). In JCP1 this had resulted in the Partnership Manager devoting only '(a)pproximately 1 day per month' to dealing with carers' issues (L1JCM1). Similarly at an operational level specialist support for carers is being eroded. For although some local JCP offices have 'carer champions' it was noted that 'there has been a tendency recently to move away from specialist adviser roles towards multi-skilling' (BDWPM2). Furthermore, individual managers have the discretion to decide whether to allow front-line advisers to attend specialist training on carers in the form of a national 'Working with Carers Event for Personal Advisers' (BDWPM2).

The design of JCP support services also finds carers occupying a marginalised position. For although a specific Work Preparation Support Programme for Lone Parents, Partners and Carers (WPS) exists, it essentially acts as a portal to carers accessing the same generic employment support available to all unemployed individuals.<sup>123</sup> Consequently carers may not have access to flexible support options which can accommodate their caring responsibilities. For example, one practitioner acknowledged in relation to the main employability training course offered in JCP2 that,

*'...the hours that they are expected to be at that opportunity is not very compatible for carers so it can be tricky for them to access that sort of thing.'* (L2JCP1)

Moreover, although individuals can request access to a specific course provided via an external provider, current commissioning practices require each request to undergo a district level tendering process. This can potentially result in a carer being expected to attend a course 50 miles away which

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<sup>122</sup> 'Education, Local Authorities Agenda's, Probation/Offenders, Drugs and Alcohol, Carers' (L2JCM1).

<sup>123</sup> Providing support with 'training, part-time work, voluntary work, job search, help with CV writing or interview skills, work trials, self-employment and in-work financial help (BDWPM2).

as noted by one practitioner 'is just not practical.....they want the course that they've found that is convenient to them' (L2JCP1). Alternatively carers can, if they choose, volunteer to join the mainstream JCP Work Programme. However once they join the programme they are subjected to the same conditions as all other unemployed participants, including no access to replacement care costs (L2JCM1); and being '.....subject to a reduction in benefit, if they fail to participate' (BDWPM2). Furthermore, although carers can access the Flexible Support Fund (FSF) to assist with the costs of interview clothes, travel costs and replacement care costs, the FSF does not contain '...a 'ring-fenced' budget for carers' (BDWPM2). Consequently, carers compete alongside all other unemployed benefit claimants for access to these financial resources. These examples illustrate the peripheral treatment of carers within this domain by revealing how the design and provision of JCP support is targeted at meeting the needs of unemployed workers, rather than providing carers with the specific, comprehensive and flexible support they require to ensure their care-related needs are met.

## **7.4 Part B: Statutory support in employment**

### **7.4.3 Weakness of carers' employment rights**

Carers' rights in the employment domain are not contingent upon the care-receiver's statutory entitlements and carers are not required to provide any proof of their caring role or the care-receiver's circumstances. However, carers' rights to take time off in an emergency or to request flexible working constitute 'weak' or 'empty' rights respectively. For both sets of 'entitlements' remain entirely dependent on the employer determining the reasonableness of each carer's request, and provide no statutory financial protection for carers. This ensures that the poverty risks arising from reconciling work and caring roles are privatised. For example, the legislation relating to taking time off in an emergency prescribes no minimum standard of financial protection to accompany the right to time off. Consequently, although some employers are noted to voluntarily extend carers' rights beyond the legislative requirements,<sup>124</sup> many employers only provide unpaid care leave,

*'...it's difficult to get a feel for really how many employers are actually providing....paid [care leave], I suspect not many, I think quite a lot it's just literally as it is on the statute book' (ETSM1).*

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<sup>124</sup> For example, Hertfordshire County Council provides employees with 5 days paid leave to deal with emergencies involving dependents and an extra 20 days unpaid care leave each year (Carers UK et al., 2011, p. 12). In the Metropolitan Police paid leave is doubled if the individual has multiple caring responsibilities (Department of Health, 2010c, p. 46).

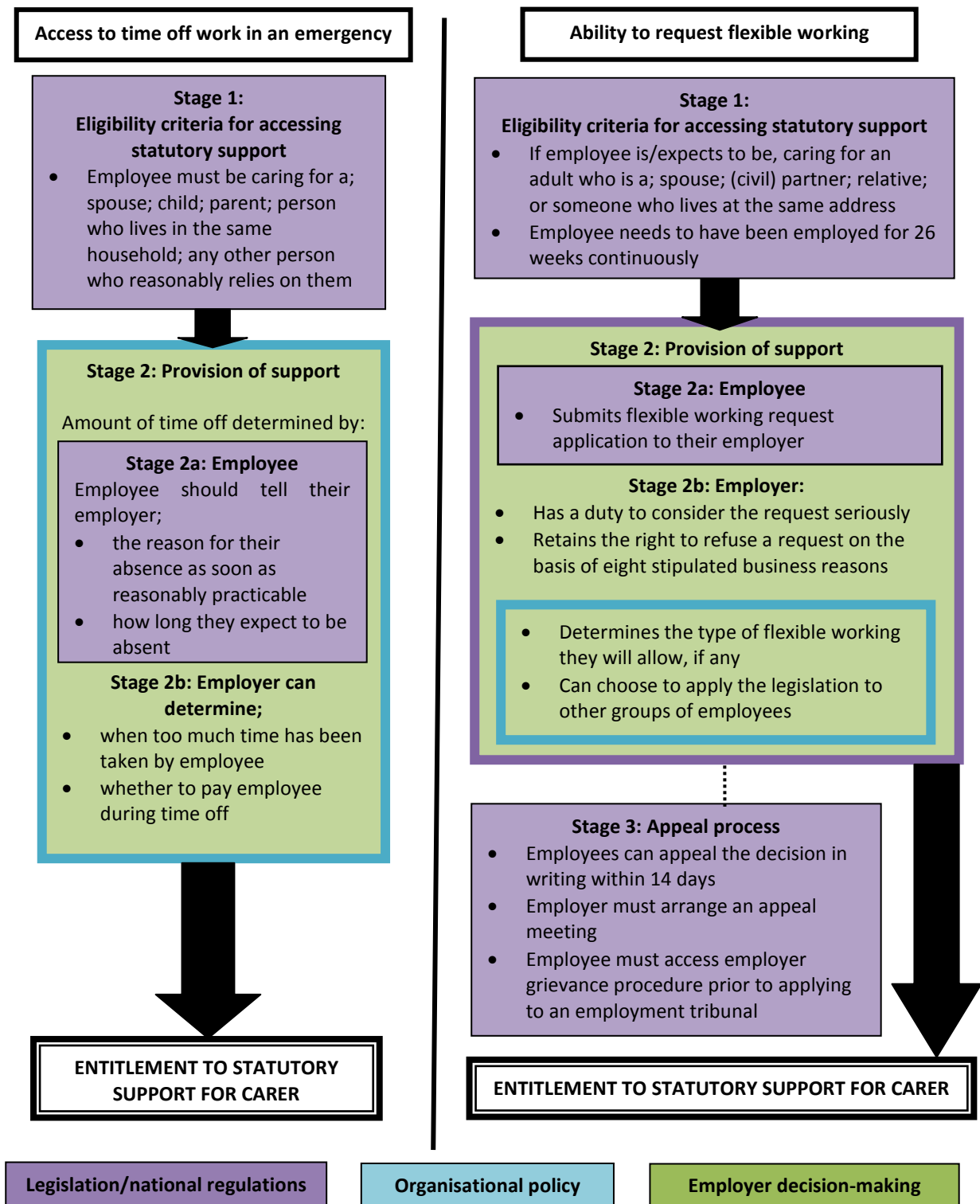
Meanwhile, the legislation stipulates that employees have a statutory right ‘.....to be permitted by his employer to take a reasonable amount of time off’ (HM Government, 1999), and allows employees to activate this right with immediate effect. However, ultimately it is the employer who determines what is ‘reasonable’ in terms of the length and frequency of employees’ absences, ‘if an employer feels that an employee is taking more time off than they can cope with, they should warn them of this’ (Carers Direct, 2011i; Directgov, 2012o). Even more extensive weaknesses are contained within the flexible working legislation due to the state setting no absolute statutory requirement that all employers have to adhere to. The legislation does not create flexible working or even an automatic right to flexible working. Instead it only grants employees the statutory **right to request** contract variation and only places a duty on their employer **to consider** the request seriously (HM Government, 2006c). Meanwhile, employers retain the discretion to determine which types of flexible working arrangements, if any, to allow within their organisation. They also retain the right to refuse a flexible working request on the basis of eight stipulated business reasons.<sup>125</sup> Although employees have the right to challenge an employer’s unfavourable decision about their request,<sup>126</sup> they may be unwilling to engage in a formal dispute with their employer about this. The rights of carers to access statutory support in the employment domain are therefore revealed to be weak.

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<sup>125</sup> These include; the burden of additional costs; detrimental effect on ability to meet customer demand; inability to recruit additional staff; inability to reorganise work among existing staff; detrimental impact on quality; detrimental impact on performance; insufficiency of work during periods the employee proposes to work; planned structural changes (HM Government, 2011, p. 9).

<sup>126</sup> See Stage 3, Figure 33 (Carers Direct, 2011d).

Figure 33: Institutional process for carers accessing statutory entitlements in employment



#### 7.4.4 Marginalisation of carers in the design of employment legislation

Similarly to the JCP domain, the design of the employment legislation is revealed to be targeted at meeting the needs of wider groups of beneficiaries, which ensures that carers' specific needs remain

marginalised by state policies. In the case of taking time off in an emergency, the legislation covers a wide range of contingencies, including '.....when a dependant falls ill, gives birth or is injured or assaulted' or dies (HM Government, 1999), which ensures that this statutory right applies in cases which are not typically classed as caring situations. Moreover, the restrictions that employers can apply to the amount and frequency of time that employees can take off, and the fact that the legislation does not cater for planned eventualities, fails to address the needs of informal carers. For example, carers dealing with regular care crises or having to take time off to accompany a dependent to planned medical appointments remain beyond the protective scope of the legislation and may therefore remain reliant on using other types of leave arrangements. Two interviewees with caring responsibilities commented that they had to take 'flexi or annual leave' (L1LAP2) or sick leave in order to attend the care-receiver's hospital appointments or provide care to the care-receiver during extended periods of illness,

*'[W]hen [my relative] was ill for a long time, I went off sick and did it that way.....otherwise I'd have used all my annual leave. So I went off sick which is what a lot of people do' (L1LAP3).*

The inadequacy of the legislation for meeting the needs of long-term, substantive carers in particular illustrates how the purpose of this legislation is to support employees generally, rather than carers specifically.

Elements of the design of the flexible working legislation also undermine the extent to which it addresses the needs of carers. Firstly certain categories of care relationships, including carers providing care to a friend, neighbour or more distant relatives, which accounts for approximately '....20 per cent of carers, are currently excluded from the statutory right to request flexible working (Department of Health, 2008, p. 88). Secondly, the legislation is not responsive to all carers' needs. For example, the flexible working application can take up to 14 weeks to process which is not conducive for carers who are attempting to manage the sudden onset of, or sudden increase in, a caring role (HM Government, 2011, p. 12). Employees can only make one request in any 12 month period which may be problematic for carers engaged in unpredictable caring situations (HM Government, 2011, p. 12). Moreover, the requirement that carers must have worked continuously for their employer for 26 weeks<sup>127</sup> prior to making a request can undermine their labour market participation if they are not guaranteed flexible working from the start of their employment contract. The Coalition Government's recent consultation (HM Government, 2011) to extend this statutory right to all employees could marginalise the needs of carers further. Although one

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<sup>127</sup> The Government justified this restriction, noting that an employer needs to be assured of an employee's commitment before changing the organisational structure to accommodate the employee's needs (HM Government, 2011, p. 11).

interviewee considered that this proposed extension would help carers because it would 'normalise.....flexible working' and '.....might make more carers come forward because ....you wouldn't necessarily have to declare that you are a carer' (ETSM1). However, by creating a universal right for all employees, carers' requests will be placed in direct competition with those of all other employees. A previous government consultation document acknowledged that this could potentially undermine individual carers from accessing flexible working because requests will be managed chronologically rather than necessarily responding to those with the 'greatest' needs (HM Government, 2006a, p. 7).

## **7.5 Care services domain**

The treatment of carers in the care services domain replicates the key themes emerging across the other domains, as well as containing a unique feature. Firstly, carers' statutory rights are revealed to be weak on account of their derived nature and in comparison with care-receivers' statutory entitlements. In terms of the former, this is the one policy domain where meeting the carer's support needs is to some extent necessarily contingent upon the care-receiver's own statutory entitlements if they wish the care they provide to be directly substituted by replacement care services. Even so, the legislative framework exacerbates the weakness of carers' rights by making access to all forms of carer support unnecessarily contingent upon the care-receiver. Secondly, the way in which local authorities structure and organise their institutional processes can marginalise carers yet further. Maintaining separate institutional processes for each member of the caring dyad can result in those processes relating to the carer being assigned a peripheral status within the social care system. This structuring can also have significant implications for the inter-related needs and risks faced by the caring dyad being recognised and adequately protected.

### **7.5.1 Carers' derived and weak rights to statutory support**

The legislative framework underpinning the care services domain consists of separate pieces of legislation and policy guidance for each member of the caring dyad. Figure 34 illustrates the two distinctive institutional processes through which the members of the caring dyad access statutory support to meet their care-related needs: the care-receiver's community care assessment process (Process A); and the carer's assessment process (Process B). It reveals how the strength of each member's rights differs at each stage of the institutional process:

- Stage 1: determining eligibility to access the assessment process;
- Stage 2: determining eligibility to access statutory support;

- Stage 3: determining the type and level of statutory support to be provided.

Carers' rights to statutory support are revealed to be considerably weaker than those of care-receivers'. This is due to the less robust legislative requirements placed on local authorities to meet carers' needs and the contingent nature of their rights. For the ability of carers to engage in either institutional process (A or B) remains dependent on the care-receiver's entitlement to a community care assessment.

In the case of care-receivers, under the NHS and Community Care Act 1990 local authorities have a statutory duty to carry out a community care assessment if it appears that an individual may be in need of community care services (Stage 1) (HM Government, 1990). Following on from the assessment, if the local authority has identified an individual to have eligible needs (Stage 2), they have a duty to provide community care services or funding<sup>128</sup> to meet those needs (Stage 3). A range of legislation sets out the type of generic community care services that local authorities have a duty to provide (HM Government, 1968, 1970, 2006b). Even so, the exact level and type of support provided in each individual case is ultimately determined by the specific services local authorities' commission and the individual decision-making of practitioners and members of the Resource Allocation Panel (Stage 3a and 3b). The policy guidance recommends that practitioners take carers' views into account during the care-receiver's community care assessment 'whether or not the carer wishes to have a separate carer assessment' (Department of Health, 2010a, p. 32). Even so, this inclusion does not constitute a statutory right. Local authorities only have an obligation during the community care assessment process to; consult the carer if it is considered to be 'appropriate'; and take reasonable steps to reach agreement with the service user and their carer about the community care services to be provided (Department of Health, 2004). This obligation to involve the carer is only characterised as a duty if the care-receiver lacks capacity (Department of Health, 2004).

Meanwhile, carers' rights to statutory care and support contain more substantive weaknesses. Local authorities only have a duty to offer a carer assessment if the carer is providing or intending to provide 'a substantial amount of care on a regular basis' (HM Government, 1995, p. 1); and the person they care for is considered to be eligible to receive a community care assessment (HM Government, 2000). This makes carers' rights to access statutory support a derived right. Moreover, while the local authority has a duty to **consider** whether the carer has eligible needs, they are under no statutory obligation to provide statutory support to meet those needs (HM Government, 2000; Department of Health, 2010a, p. 33). This discretion applies even if the carer is

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<sup>128</sup> In the form of a Direct Payment (HM Government, 2001).



assessed to meet a critical or substantial eligibility banding (Carers Direct, 2011g).<sup>129</sup> 'Carers services' are also more ambiguously described in the legislation as "...any services which the local authority sees fit to provide; and will in the local authority's view help the carer care for the person cared for" (HM Government, 2000). This ambiguity and discretionary power to provide carers services has permitted significant differences to emerge across local authorities in the types of carer support provided. Moreover, the removal of ring-fencing from the Carers Grant<sup>130</sup> in 2003 by central government was considered by some interviewees to have conveyed the message to local authorities that the provision of carer support services is optional and made carers services more susceptible to budget cuts.

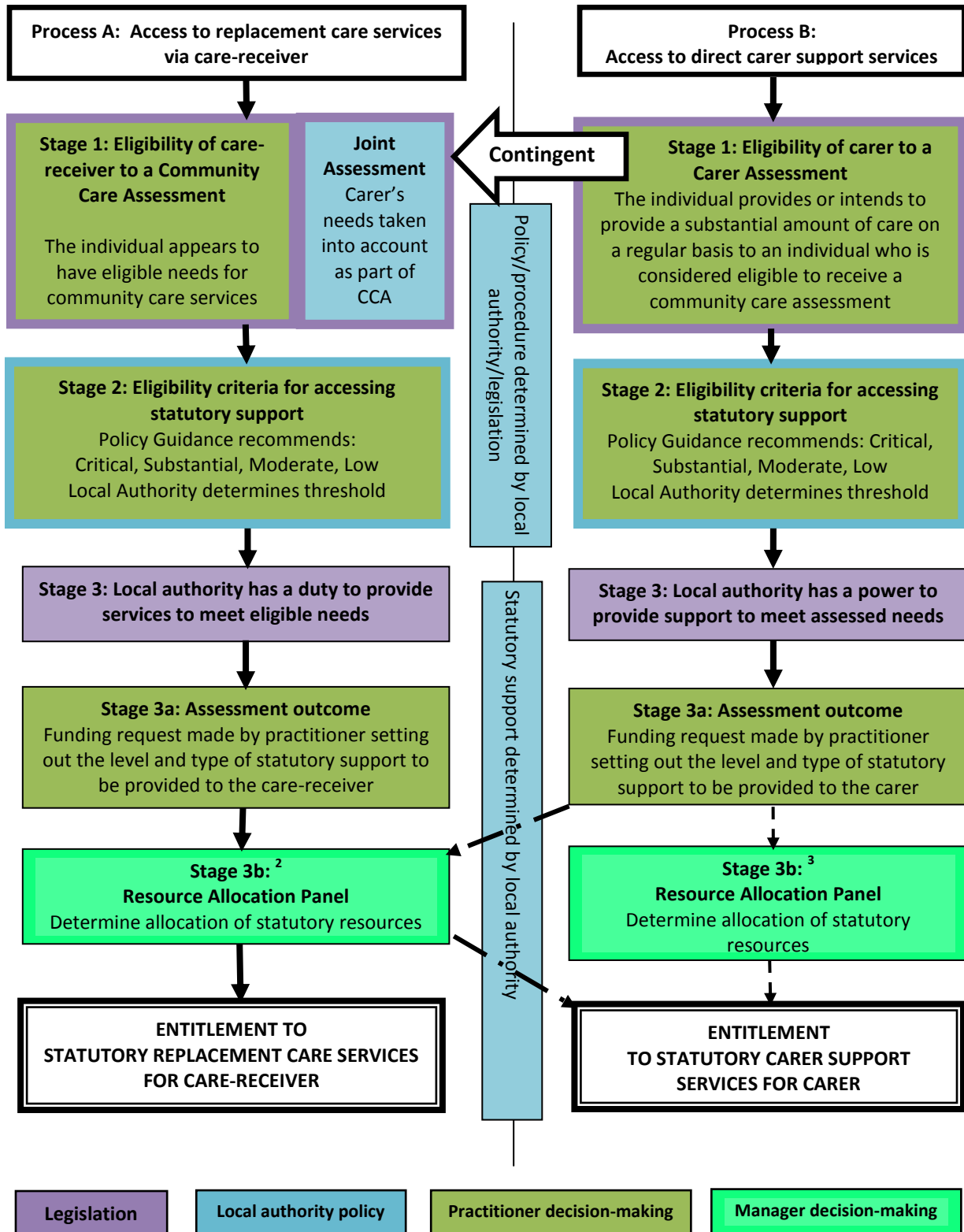
*'[C]arers can be a fairly soft option, and it's one of those things that they can trim back' (L1TS1M).*

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<sup>129</sup> Although, the guidance states that 'a local authority could not adopt a policy never to exercise the power to provide services to carers, as this would amount to a fettering of its discretion' (Department of Health, 2010a, p. 33).

<sup>130</sup> Implemented in 1999 by New Labour to push local authorities to invest in specific support and services for carers (Lloyd, 2006a; Yeandle et al., 2007, p. 28).

Figure 34: Institutional processes for the caring dyad accessing statutory care services support <sup>1</sup>



Note:

<sup>1</sup> Figure 34 illustrates the institutional processes used by the local authorities in my two research sites. Other local authorities will follow a similar overarching framework but policies and statutory outputs may vary.

<sup>2</sup> Stage 3b: The alternate black dashed and dotted arrows denote the new RAP process for carers in LA2 going via the care-receivers' RAP process.

<sup>3</sup> Stage 3b: The black dashed arrows denote the RAP process for carers in LA1.

### **7.5.2 Disaggregation of the caring dyad and the marginalised position of carers**

The care services domain contains a unique feature relating to the disaggregation of the caring dyad which has significant implications for the state's treatment of informal carers and care relationships. The substantial discrepancies which exist in the strength of the caring dyad's statutory rights have arguably promoted the development of separate institutional processes which disaggregate the members of the caring dyad, requiring them to make separate applications to access statutory support. However, the level of discretion local authorities are permitted in how they structure and organise their institutional processes can reinforce the artificial separation of the caring dyad. For example, both LA1 and LA2 were found to use the two assessment processes instrumentally to access specific types of services; to use different teams or agencies to administer each assessment process; and to construct separate resource allocation systems for carers and care-receivers to access statutory support. Maintaining the separateness of these institutional processes can have a number of implications. Firstly, it can exacerbate and entrench the disaggregation of the caring dyad within decision-making processes which can undermine the provision of holistic support for managing the inter-related risks which care relationships face. Secondly it can create a hierarchical distinction, whereby care-receivers' needs and institutional processes are prioritised within the social care system while carers occupy a more marginalised and peripheral position. Each of these ways in which local authorities exacerbate the disaggregation of their institutional processes will now be analysed in turn.

The explicit disaggregation of carers' and care-receivers' assessment processes for the instrumental purpose of accessing specific services was considered by a government interviewee to be a misrepresentation of government intentions (NGPR). They noted that whether carers have a separate carer assessment (B) or have their needs jointly assessed as part of the care-receiver's community care assessment (A), both institutional processes should offer equivalent access to carer support services. However, both local authorities had designed their institutional processes so that any joint assessment (A) could only lead to replacement care services being provided directly to the care-receiver. If carers needed their own statutory support services (including carers' personal budgets, carer break services<sup>131</sup> etc.) they are required to have their own separate carer assessment (B). Furthermore, the potential for this administrative separation of the caring dyad to undermine a holistic assessment of the caring dyad's needs being conducted, may be exacerbated by separate staff groups being assigned to administer each assessment process. Both local authorities used practitioners from their community care teams to conduct the care-receiver's community care

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<sup>131</sup> Where these are categorised as a carer service.

assessments. Meanwhile, specialist carer assessors from either the local authority (LA1)<sup>132</sup> or a third sector agency (LA2) conducted their carers' assessments. These segregated staffing systems had been introduced to improve the quality of the support that carers could access. Specialist carer assessors were considered to be more 'carer focused'; more able to provide 'up to date' and accurate information; and to have more time to support carers (L2LAP1/L2LAP2/L1LAM3).

*'....[Q]uite often the carers tell us things that they haven't said to the social worker.... the kind of feedback comments we get is, its the first time they do feel they have been listened to by somebody.....I suppose because we are the only person that....really kind of focuses on them' (L2TS1M1).*

Even so, the concerns raised in the statutory guidance that by delegating responsibility for carers assessments wholesale '....the need for effective holistic assessments to include both carers and cared for people's experiences in one process' is undermined (Department of Health, 2001, p. 24), was reflected in my data. For while carers were considered to receive better quality carers assessments, the potential remained for carers' needs to be marginalised and neglected within the care-receiver's community care assessment even though this is the main avenue through which carers access replacement care services.

*'The [community care team] social worker....should go out and look at the whole household....but they go out and look at the cared for person....and put services in without even considering the carers if they want to'. 'We had one the other day, the carer...was desperate for a sitting service....The social worker went out....went through the community care assessment, came back and didn't put a sitting service in. So I phoned to find out why....and [the social worker] said 'oh she didn't mention it when I was there' and I said 'did you offer it to her' and [they] said 'well no, I didn't think about it' (L2TS1M1).*

Moreover, in LA2 using different practitioners to undertake each assessment process was acknowledged to have created a 'huge' communication gap which had undermined the inter-related needs of the caring dyad from being recognised.

*'...How do you know as a social worker you are setting up the right care package if you haven't talked to [the carers' assessor] about what the carer needs are, because you haven't spoken to the carer. And then saying to [the carers' assessor] you're saying the carer needs this, this and this, actually a lot of that is resolved if the care plan is right for the cared for, so talk to the social worker and try and have some influence over the care plan....its about bridging that gap' (L2LAM2).*

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<sup>132</sup> In LA1 if a generic practitioner was already conducting a community care assessment with a care-receiver they would also undertake the carer's assessment in order to 'provide continuity' (L1LAM3).

These segregated assessment systems could therefore inhibit the provision of holistic statutory support which serves the needs of the care relationship as a whole.

The construction of separate resource allocation systems for managing care-receivers' and carers' funding requests (see Figure 34) can also exacerbate the marginalisation of carers within social care funding decisions; and undermine the provision of holistic care packages to address the inter-related needs of the caring dyad. For this reason LA2 were amending their systems to enable all carers' funding applications to be directed via the care-receivers' resource allocation panel process.

*'Carers can be seen as very peripheral even within community care work within locality teams...., its seen as.....nice to do if you have got the time, but we are really focused on the cared for person here....'. However, 'When you read.....maybe 10 carers assessments in a row of people who are struggling to balance work with full-time caring....you read about a 95 year old carer saying I don't know how much longer I can keep doing this, I am exhausted.....When you read this repeatedly every day it really puts it into perspective and I think that's the balance that is missing at the moment within our own operational teams. You see one side but not the other'. By 'integrat[ing] carers' needs into the bigger community care picture' decision-makers should reflect more on whether '.....we are doing enough in terms of care packages to cared for people because we can't expect carers to keep doing what they're doing.' (L2LAM2)*

Even so, merging the two resource allocation processes may not necessarily ensure that holistic and comprehensive funding decisions are made in relation to each care relationship. One interviewee noted that maintaining separate budgets for each member of the caring dyad leads to expenditure on either member being perceived as an expense to the adult social care system (NTSPR). Consequently both sets of funding applications may be subject to scrutiny in an attempt to reduce costs. Even though in practice expenditure on statutory support for carers can often provide long-term savings by maintaining care relationships (L1LAM3), and reducing the need to provide more expensive forms of care, such as residential care (NTSPR).

The wellbeing of care relationships could also be undermined where local authority policies and resource allocation decision-makers insist that the beneficiary of any statutory support request is clearly assigned and demarcated. In these cases funding decisions can fail to capture the inter-relational dimension of care and undermine the provision of holistic support and protection that is required by care relationships. In LA2 carers' personal budgets can only be used to pay for support that only they would benefit from (L2LAM2). Consequently in a case involving a caring dyad who lived together, a funding request that was made for the provision of support to clean an injured carer's kitchen was refused because the carer's service would '....benefit the cared for person

because it was a kitchen which she had to use to prepare him food.....' (L2TS1M1). Similarly it was noted 'we wouldn't let the [carer] spend their direct payments on buying....domestic support for their mum' (L2LAM2). However, one practitioner questioned this policy from the carer's perspective, stating,

*'I don't have the time to do, amongst everything else I'm doing for this person, their housework and that's what I would want to use the direct payment to offload the stress for me...'* (L2LAP2)

However other's viewed this policy to protect carers' rights to their own statutory support,

*'I suppose what [LA2] is saying, this is ...to thank you for caring for the cared for and so rather than you using your money to pay for something for the cared for....it's purely for you....'* (L2LAP1).

However, the more local authorities attempt to stipulate how the caring dyad should configure their statutory support, the less freedom the caring dyad has to determine for itself how best their unique care relationship can be supported by the state.

## **7.6 The fragmentation of the policy environment**

This final section explores the fragmentation of the overarching care policy terrain from two perspectives. Firstly, it exposes the degree to which localism together with organisational and practitioner discretion can exacerbate the system's complex construction by proliferating the ways in which institutional processes are operationalised; and the statutory support options that are made available to care relationships on account of where they live and work and which practitioner they are assessed by. Secondly, it considers how the fragmented structure of the overarching system can undermine the caring dyad successfully accessing statutory protection against their care-related risks.

### **7.6.1 Impacts of localism, organisational and practitioner discretion on the policy environment**

The three main policy domains are subject to differential levels of decentralisation and discretionary decision-making leading to some elements of statutory support being more greatly affected by territorial and practitioner inequalities than others. The employment sub-domain contains the highest levels of variation in the statutory support available to carers. This is due to the operationalisation of carers' employment rights taking place at the level of individual employer

organisations. Relying on disparate organisations to implement and interpret statutory regulations contributes to innumerable permutations existing in the type and level of employment support employers offer to employed carers. This inconsistency is institutionally promoted by the weakness and lack of specificity contained within the legislative framework about carers' employment rights. Both these factors also make the development of care-related policies and support susceptible to the influence of organisational culture. This may undermine the quality and comprehensiveness of provision offered particularly where organisations consider carer support to be '.....good family friendly stuff but not really critical to the business' (ETSM1). Moreover, this is the one domain where, due to the legislation being left to non-statutory agencies to implement with no government oversight, carers may unwittingly find themselves lacking access to even the basic statutory provisions. One interviewee noted unlawful institutional absences to exist in work places due to some organisations lacking awareness of their basic statutory responsibilities.

*'....I think...it can be very difficult for businesses, particularly very small businesses to really read through all the legal jargon and actually understand what they are supposed to do and why it's important for them' (ETSM1).*

All these factors produce significant inequalities in the level of statutory protection employed carers have access to depending on where they work.

The JCP employment support and care services domains also experience high levels of inconsistency across their policies, practices and statutory outputs at a locality level. Both domains are underpinned by national regulatory and legislative frameworks respectively which set out the overarching statutory support which should be provided. However, the joint influences of localism and personalisation permit statutory agencies and practitioners' significant levels of discretion in determining the delivery of statutory responsibilities and support. This contributes to practitioner-based and territorial inequalities emerging in the statutory outputs provided to care relationships across and within localities. For example, across JCP localities,

*'....[D]istrict managers and advisers now have more flexibility about the provision they make available and how they allocate money from their budget to meet local priorities so the support on offer may vary from district to district' (BDWPM2).*

Consequently, territorial inequalities existed across the two research sites in the treatment of carers attending training courses,<sup>133</sup> and in the provision of funding from the Flexible Support Fund.<sup>134</sup>

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<sup>133</sup> In LA2 carers in receipt of IS are charged for attending college courses, while in LA1 any carers who join the council's Passport to Leisure scheme can attend college courses free of charge (L1LAM2).

Meanwhile in the care services domain, the level of decentralisation and discretion permitted in the operationalisation of the national legislative framework ensures that differences exist in the design of local authorities' eligibility policies,<sup>135</sup> financial charging policies,<sup>136</sup> and the type and categorisation of care services they provide. This can lead to differential statutory outputs emerging across even similar care relationships depending on where they live. The lack of central government oversight of local authority policies can also allow territorial inconsistencies to persist. For example, LA1 had deviated from the statutory guidance and developed their own unique eligibility bandings<sup>137</sup> and criteria for determining carers' eligibility to statutory support which, contrary to the national guidance, were partly contingent on the care-receiver's circumstances. The type of statutory support services provided to meet the needs of the caring dyad could also vary across localities, with carers services being subject to more territorial variation due to their ambiguous and discretionary nature. Key territorial differences were found across care-receivers services in relation to night-time support services<sup>138</sup> and day care services.<sup>139</sup> Meanwhile discrepancies were found across carers services, in relation to counselling services,<sup>140</sup> emergency response schemes, training courses and the use of carers' personal budgets.<sup>141</sup> Substantive differences were also found in the categorisation of sitting services, with LA1 categorising it as a free carers service, while in LA2 it had recently been re-categorised as 'a chargeable domiciliary care service' for the care-receiver. Due to different assessment processes, eligibility criteria and charging policies applying to this specific service across the two localities, more care relationships were considered eligible to access sitting services in LA1 than LA2.

In each of these domains, practitioner and manager decision-making also plays an influential role in determining the statutory support options which the caring dyad can access. This can contribute to

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<sup>134</sup> Access to the FSF for interview clothes required '....proof of job interview' in LA1 (L1JCP1); meanwhile in LA2 'there has to be the promise of a job, not just an interview' (L2JCP1).

<sup>135</sup> One interviewee noted, '....the [national eligibility] FACS criteria are so vague and so open to interpretation.....which is why there is disparity between local authorities' (L1LAM1).

<sup>136</sup> Discussed previously in Section 6.4.2.1.

<sup>137</sup> Basic, standard and enhanced instead of the national policy prescribed low, moderate, substantial and critical.

<sup>138</sup> LA1 could '....offer....2, possibly 3 night sits...a week...It's a push to get through....and it kind of requires a lot of discussion' (L1LAM1); LA2 could provide a service under exceptional circumstances, which 'is very unlikely to be agreed....on a regular basis'; LA3 had a specific service providing 'welfare checks during the night' between 11pm-7am.

<sup>139</sup> LA1 could provide local authority day care between 10am-4pm including transport. In LA2 day care places are spot purchased using a fixed personal budget amount. Finding a suitable service depends on 'where you live [and] how far you can travel' and the ability to pay transport costs and any top up fees (L2LAM1).

<sup>140</sup> LA2 provide 12 free sessions, LA1 has no such service.

<sup>141</sup> In LA2 personal budgets can only be used to pay for carer breaks (e.g. driving lessons and massage treatments) (L2TS1M1). LA1 also allows carers to purchase material goods for the care-receiver to ease their caring role (e.g. recliner chairs, tumble dryers (L1LAP1); 'waterproof bedding' (L1LAM3)).



inconsistent entitlement outputs emerging across care relationships within the same locality or organisation. For example in the employment domain it was noted in relation to flexible working requests,

*‘...[P]eople’s experience can be very, very, varied even in a really good employer that wins.....top working families awards, you can still get examples of individual carers who will have a difficult experience because they are in a particular location with a line manager who doesn’t get it...’ (ETSM1).*

Meanwhile, in the care services<sup>142</sup> and JCP support domains, personalisation plays a role in producing these unequal outputs. For example, JCP practitioners are expected to devise personalised support plans which tailor the level and type of JCP support ‘to suit the individual’s circumstances’ (BDWPM2). Moreover, ‘....no fixed limits’ are applied to ‘how much can be spent on any one individual....’ (BDWPM2), as long as it increases ‘....the likelihood of that person moving into work as a result’ (L2JCP1).

In contrast, the centralised administration of the cash benefits system acts as a protective factor against both territorial inequalities and practitioner based inconsistencies occurring. In most cases the regulations which apply to care-related benefits apply nationally. Administrators who process benefit applications rely on the same prescriptive regulatory guidance issued by the DWP (Department for Work and Pensions, 2012). This promotes consistency across different practitioner’s decision-making so that individuals with similar circumstances should receive the same entitlement outcome.<sup>143</sup> However, although the cash benefits system operates as the most predictable domain in relation to the consistency of the statutory entitlements on offer, the ease of accessing these benefit entitlements is undermined by the fragmented structure of the benefits system itself as demonstrated previously in Figure 29.

## **7.6.2 Implications of the fragmented policy environment for individual care relationships**

The overarching care policy system’s fragmented construction undermines the caring dyad successfully accessing statutory protection in a number of ways. Firstly, the segregation of the system into policy silos requires individuals to make separate applications to each institutional entry

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<sup>142</sup> Discussed previously in Section 6.4.1.1.

<sup>143</sup> Uniformity across the assessed benefit entitlements of individuals is not guaranteed in the case of Income Support where Decision Makers may be required to apply their discretion to determining whether someone is regularly and substantially caring (Department for Work and Pensions, 2012, para. 20117).

point in order to access the level of statutory protection they require, with the number of applications multiplying with each type of need and risk that they face. Carers may also have to complete applications on the care-receiver's behalf as well as for themselves, indeed the derived nature of many 'carer entitlements' may make this unavoidable. Consequently individuals may find themselves attempting to access, and negotiate with, an extensive range of statutory agencies and non-statutory organisations including employers. This illustrates how the fragmented structure of the policy environment creates a complex and time-consuming terrain for the caring dyad to navigate. Moreover, each additional policy silo proliferates the eligibility criteria which the caring dyad are required to meet. As already demonstrated in Chapter 6, individuals may not find their eligibility replicated across different policy mechanisms due to different, sometimes contrasting characteristics being applied. This lack of consistency adds to the systemic complexity by exacerbating the opacity and unpredictability of the institutional terrain which can undermine adequate protection being provided to the caring dyad.

Secondly, in order for carers to be adequately protected against the diverse risks which they face complimentary interactions between policy regulations are required. However, a range of mutually exclusive policy regulations exist which either affect an individual's own entitlements or create conflicts across the entitlements of the caring dyad. This dissonance can create dilemmas for individuals and care relationships as they seek to address their needs within existing statutory constraints. As noted in Chapter 6, although the carer assessment legislation considers it to be a carer's right to be supported to engage in employment and education (HM Government, 2004), Carers Allowance exempts carers from earning more than £100 per week or engaging in full-time education.<sup>144</sup> Moreover, informal carers who are employed by the care-receiver using a local authority direct payment may forfeit their entitlement to CA,<sup>145</sup> a carer assessment and carers services on account of their earnings and employment status.

Thirdly, seamless intersections across policy silos are needed in order to insure against inadequate statutory protection. However, the segregated structure of policy silos contributes to the formation of agency specialisms and protectionist attitudes towards agency budgets. Added to which ambiguous statutory obligations allow agencies to determine the extent of their responsibilities in relation to areas of need which extend cross multiple domains. Both elements contribute to disjointed policy intersections forming between the different policy silos and undermine different agencies taking shared responsibility to co-produce multi-agency solutions which ensure particular

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<sup>144</sup> Defined as 21 hours or more a week of supervised study (Carers Direct, 2011c; Directgov, 2012h).

<sup>145</sup> Even if they continue to provide over 35 hours of unpaid informal care each week (BDWPM1).

needs are met. This is illustrated in the case of carers in work or seeking work who face statutory support vacuums across domains, leaving them inadequately protected against the risks of reconciling their work and caring roles. For example JCP support with funding replacement care only covers carers during the job-seeking process (BDWPM2); once in work few employer organisations provide care vouchers to subsidise the provision of care services (Department of Health, 2010c, p. 47); although local authorities are considered by many to be the key source of replacement care support for employed carers (L2LAM2), one interviewee's experience was that '.....[social services] are not going to set up daily care so you can go out to work' (L1TS2M). Meanwhile, the duty that local authorities have to consider the impact that the caring role might have on a carer's work or wish to work (Department of Health, 2001, 2010a; HM Government, 2004), did not extend to the resource allocation panel in LA2 agreeing to provide a carers' personal budget to cover the cost of back to work training, which was deemed to be the role of Jobcentre Plus instead (L2TS1M1).

Finally, the segregation of policy silos can impact on the knowledge and awareness of individual practitioners about how other elements of the wider policy system functions. This can lead to practitioners providing inaccurate information to individuals about their potential entitlements in other policy domains. For example, several local authority practitioners erroneously considered low need Tier 3 care-receivers to be eligible to claim Attendance Allowance in order to pay for the care they require privately (L1LAM1). Meanwhile this systemic fragmentation can also affect knowledge transfer within domains. For example, practitioners administering one cash benefit mechanism are under no obligation to advise claimants about their other potential benefit entitlements (BTSP1).

## **7.7 Conclusion**

This chapter has helped to contextualise the findings from Chapter 6 by exposing the complexity of the overarching policy environment in which the statutory protection that is available for care relationships is situated. This complexity is produced by the fragmentation of policy silos, the ambiguity of regulatory frameworks, and the influences of localism, organisational and practitioner discretion, and personalisation. In turn these factors contribute to making the policy terrain unpredictable and opaque and permit institutional absences and inconsistencies to occur. This results in variations emerging in the treatment of the caring dyad and inconsistency in the level of statutory protection care relationships can access within and across localities and policy domains.

This chapter also identifies the key institutional trends found across all three policy domains which reveal how informal care is treated by the state. Carers' statutory rights often constitute weak and

empty rights. This ensures that while their need for statutory support and protection may be formally recognised by the state, in practice their actual needs and risks may remain fully or partially privatised. For this statutory weakness has encouraged and permitted agencies to consider the provision of statutory support for informal carers to be optional and discretionary; and the statutory support that is provided to be designed to meet the needs of other groups of beneficiaries rather than specifically catering for the needs of carers. Meanwhile, the derived and dependent nature of many informal carers' entitlements serves to highlight their lack of independent access to statutory support in their own right, and reflects their sub-ordinate positioning within care relationships and the policy environment. The artificial disaggregation of the caring dyad within institutional processes and decision-making also highlights how the existing system struggles to manage the inter-related nature of informal care, and recognise the complexity of the inter-related risks affecting care relationships. This can produce statutory responses which are unable to cater for the overarching needs of care relationships and which can consequently actively undermine the wellbeing of the caring dyad. All of these trends highlight how informal carers' entitlements to statutory support are weakly embedded and marginalised within the overarching policy environment. This provides further evidence that the state does not treat informal care as a social risk because the legislative framework and resulting statutory provision fails to provide the comprehensive and holistic approach required for recognising and protecting care relationships against the care-related risks they face. Consequently, the ensuing complexity, fragmentation, unpredictability and opacity of the care policy environment ensures that many informal carers' care-related risks remain fully or partially unrecognised and unprotected by the state.

This chapter has highlighted how the complexity of the overarching care policy environment can create significant barriers for the caring dyad successfully navigating access to their overarching statutory entitlements by creating entitlement conflicts and undermining the knowledge and awareness of actors engaged within the policy environment. In the final analysis chapter, the focus turns to analysing the complex negotiations that take place between the different actors engaged within these institutional processes and how institutional arrangements and personal interactions and attributes can influence the entitlement outputs of the caring dyad. This final element of the analysis will expose the institutional terrain as a place of potential conflict which can have negative implications for the social relations of the actors involved. It also considers how the system itself may produce or exacerbate poverty and welfare risks.

## **Chapter 8: Actors and negotiations affecting access to statutory protection**

### **8.1 Introduction**

The previous analysis chapters have discussed the way in which, the characteristics of the caring dyad, and the construction of institutional structures and processes in the care policy environment, play an influential role in determining the caring dyad's entitlements to statutory support and protection against care-related risks. This final analysis chapter reveals how the caring dyad's access to the statutory support that is available can also be significantly influenced by the inter-personal interactions and attributes of the actors engaged in the policy environment.

The caring dyad's access to statutory protection is revealed to be contingent upon complex chains of negotiations taking place between different actors at different stages of each institutional process. These interactions may involve the members of the caring dyad; practitioners and managers from statutory agencies; third sector workers; and personnel within employer organisations. This analysis explores these negotiation processes in a number of ways. Firstly, it explores the influence that individual actors can have on negotiation outcomes which contribute to the variability of statutory support outputs emerging across care relationships. For the performance and interactions of individual actors within these negotiation processes can be significantly affected by their own personal attributes; their adopted roles, strategies and assumptions; and their respective power relations and social relations. Secondly, it examines the overarching weakness of the informal carer's position within these negotiations processes. It highlights how the caring dyad is absent from key resource allocation decision-making processes which leaves their statutory support outputs entirely dependent on statutory and non-statutory actors undertaking negotiations on their behalf. Thirdly, these negotiation processes are revealed to have the potential to produce inter-relational conflict between actors, with these tensions at times being exacerbated by the design of institutional arrangements. These factors contribute to the creation of an adversarial and demanding policy environment for actors to engage in. Furthermore these inter-personal and institutional factors are revealed to affect the extent to which the caring dyad's care-related risks are protected, maintained or exacerbated by the state, with the policy system being revealed to also produce poverty and welfare risks.

This chapter is structured as follows. Section 8.2 explores the personal and institutional factors which specifically affect the caring dyad's ability to enter institutional processes in order to access statutory protection. Section 8.3 investigates the different sets of negotiations which take place between actors within institutional decision-making processes. Throughout the chapter the extent to which these negotiations and institutional arrangements can protect against, maintain, or exacerbate, the existing risks faced by the caring dyad, or generate new risks and tensions, will be considered.

## **8.2 Personal and institutional barriers affecting access to statutory protection**

The previous analysis chapters have revealed how the institutional terrain within which the caring dyad's statutory entitlements are situated is complex and fragmented. Consequently individuals require a good knowledge, awareness and understanding of the scope and way in which the overarching policy system operates in order to successfully access the statutory protection that is available to address their care-related risks. Due to the contingent and interactive nature of the caring dyad's entitlements, this awareness needs to encompass both care-givers' and care-receivers' potential entitlements. The caring dyad can be either hindered or assisted in their ability to gain this institutional awareness by their own personal attributes and the way in which institutional structures and processes are designed.

### **8.2.1 Carer awareness and power relations**

Individuals may be excluded from the statutory support that is available on account of their own ignorance or misinformed assumptions. A key barrier to informal carers accessing statutory protection is often their lack of self-awareness that they are a carer. The concerns set out in the Carers Strategy (Department of Health, 2010c, p. 8) that individuals tend to only recognise themselves in relation to their relational role for the person they care for rather than perceiving themselves to be carers, was reiterated by interviewees (L1TS2M/L1TS1M/ETSM1),

*'...they are the husband or wife....they don't think well actually I am a carer now' (L1LAP1).*

This self-identification problem can be exacerbated by the language used within policies which can obscure their applicability to carers from being realised. For example, it was noted that access to a carer assessment may be undermined by individuals misunderstanding the term 'carer', '.....people think it means paid carer.....' (L1TS2M). Consequently one interviewee commented in relation to employment policies,

*'.....we encourage employers.....to say are you 'looking after, supporting or caring for' because if you said 'Are you a carer?', people either think.....no I don't live with my elderly mum or I don't care for her in that way, so no.'* (ETSM1).

The institutional anomalies permeating statutory regulations and the institutional opacity affecting certain statutory provisions can also exacerbate people's ignorance of their entitlements. For example as noted in Chapter 6, the eligibility regulations relating to Carers Allowance (CA) and Attendance Allowance (AA) treat income anomalously to the predominant means-tested logic of the overarching cash benefits system. Furthermore, one interviewee considered that more affluent care-receivers may also gate-keep themselves from accessing means-tested benefits entitlements due to making erroneous assumptions about the regulations and their entitlement prospects. They used the case of CR8a to illustrate this point,

*'.....if you think about Mr Average in the street they are going to do some gate-keeping, they'd say there's no way I'd get anything because I've got....a reasonable state pension, I've got some occupational pension....but they do because the [personal] allowances [for people over 65] are generous'* (BTSP1).

Meanwhile the opacity and obscurity of certain elements of the cash benefits system and interacting benefit rules may also undermine the caring dyad's awareness and ability to make informed decisions about their potential entitlements. For example, when a care-receiver is allocated a Severe Disability Premium as part of their personal allowances this can have significant implications for their carer claiming CA. However one interviewee commented,

*'People don't know what the SDP is. No-one knows if they are getting the SDP, when you ask they just have no idea.'* (L1TS2M).

Meanwhile, in the case of the Warm Home Discount scheme, individuals require awareness that their ability to access financial support with their heating costs can vary substantially across energy suppliers because individual companies are allowed to construct divergent eligibility criteria.<sup>146</sup>

The unequal power relations which exist between the caring dyad and the institutional providers of statutory support may also deter potential beneficiaries from claiming statutory support. For example, unequal power relations between employers and employees, together with the institutional weakness of carers' statutory rights in the employment domain, may make informal carers reluctant to access these employment rights. One interviewee acknowledged that carers may

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<sup>146</sup> See Appendix 4 heating cost results based on my own survey of (British Gas, 2012; eDF Energy, 2012; E.ON, 2012; npower, 2012; Scottish Power, 2012).

not want to submit a flexible working request due to the potential stigma of declaring to their employer that they are a carer (ETSM1). The state provides procedural recourse to employees in the event that their employer refuses their request,<sup>147</sup> and employed carers have legal protection from "discrimination by association" under the Equality Act 2010 (HM Government, 2010). Even so, taking formal action via either process is a time-consuming and stressful endeavour and has the potential to produce additional welfare and poverty risks for carers. Engaging in a formal dispute with their employer could undermine their working relations indelibly and make the carer's employment situation untenable.

Institutional tools can be used at a legislative and organisational level to promote greater carer awareness of their statutory rights and help to allay fears pertaining to unequal power relations. For example, several interviewees recommended that employer organisations publicise policy information and provide training to elevate the awareness of employed carers of their legal entitlements (ETSM1/L2LAM2). Meanwhile, the Carers (Equal Opportunities) Act 2004 gave local authorities a statutory responsibility to inform eligible carers of their right to a carer assessment in cases where they are carrying out an assessment of the care-receiver (HM Government, 2004). Even so, one practitioner commented,

*'...I think the majority of carers don't know there's help out there...until a crisis happens and [social services are] called in' (L1LAP3).*

Consequently, LA2 had made the decision to commission a third sector organisation to conduct carers assessments in order to promote carer awareness of their statutory right to an assessment at an earlier stage,

*'.....the voluntary sector is traditionally seen as very approachable, carers may well....approach the voluntary sector of their own volition before they come to us [Social Services],so they could access a carer's assessment earlier on' (L2LAM2).*

Using a non-statutory agency could present informal carers with a less threatening institutional interface to engage with. For several interviewees considered informal carers to be reluctant to engage with social services due to misgivings about the agency's statutory power and authority and the purpose of their involvement (L3LAP1). Social services involvement was considered by some carers to be,

*'...Very, very intrusive and a stigma', '.....I mean I've had people say to me, no I'm not getting involved with social services, no way, we will try to sort it out ourselves' (L1TS1M);*

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<sup>147</sup> See Chapter 7, Figure 5, Stage 3 Appeal Process (Carers Direct, 2011d).



and some carers were noted to,

*'...fear that social services will come in and take over. You know they'll put my husband in a home because they'll say I can't cope' (L1TS2M).*

These fears were considered by some interviewees to be fuelled by the terminology used to describe particular institutional processes such as 'carers assessments',

*'People, until you explain, tend to think they are going to be assessing my capability....about how capable they are of doing it....and for a lot of people that's frightening. They don't recognise that's it's about looking at what you do and how we can support you' (L1TS2M).*

### **8.2.2 Communication skills and personal attributes of the caring dyad**

Access to institutional systems and specific statutory entitlements can also be significantly affected by the way in which the members of the caring dyad communicate and express their need for support. One interviewee noted there to be '....key words that individuals need to mention in their referral' to increase the likelihood of triggering a statutory response from social services (L3LAP1). Moreover, explicitly demanding an assessment could result in low need Tier 3 care-receivers, who were generally assessed by practitioners to be ineligible to access a community care assessment, being able to access one (L1LAP3). Individuals who had sought advice from carer organisations were also considered to be more vociferous about requesting carers assessments, '...they are coming to you [saying] 'I'm entitled to one'...' (L3LAP1). Whether an individual is offered or provided with statutory support could also be affected by how explicit they are about their needs and the type of support they want. For example, some interviewees stated that they would only offer certain types of JCP support (L2JCP1) and a direct payment to an informal carer, if the carer had clearly specified the need for this type of support during the assessment process,

*'...I don't tend to say a lot about the direct payment to be honest with you [unless]....they said that they really needed something' (L1LAP2).*

Individuals must also make explicit efforts to access care and disability-related benefits and allowances because no automatic entitlement exists. For example, care-receivers in receipt of AA who live alone are permitted to have a second bedroom added to their housing allowance to enable their carer to stay 'on and off', however, 'You have to ask for it, you won't just get it' (BTSP1).<sup>148</sup> These examples highlight the importance of individuals using precise and confident communication to gain access to the statutory protection that is available. This can disadvantage certain individuals,

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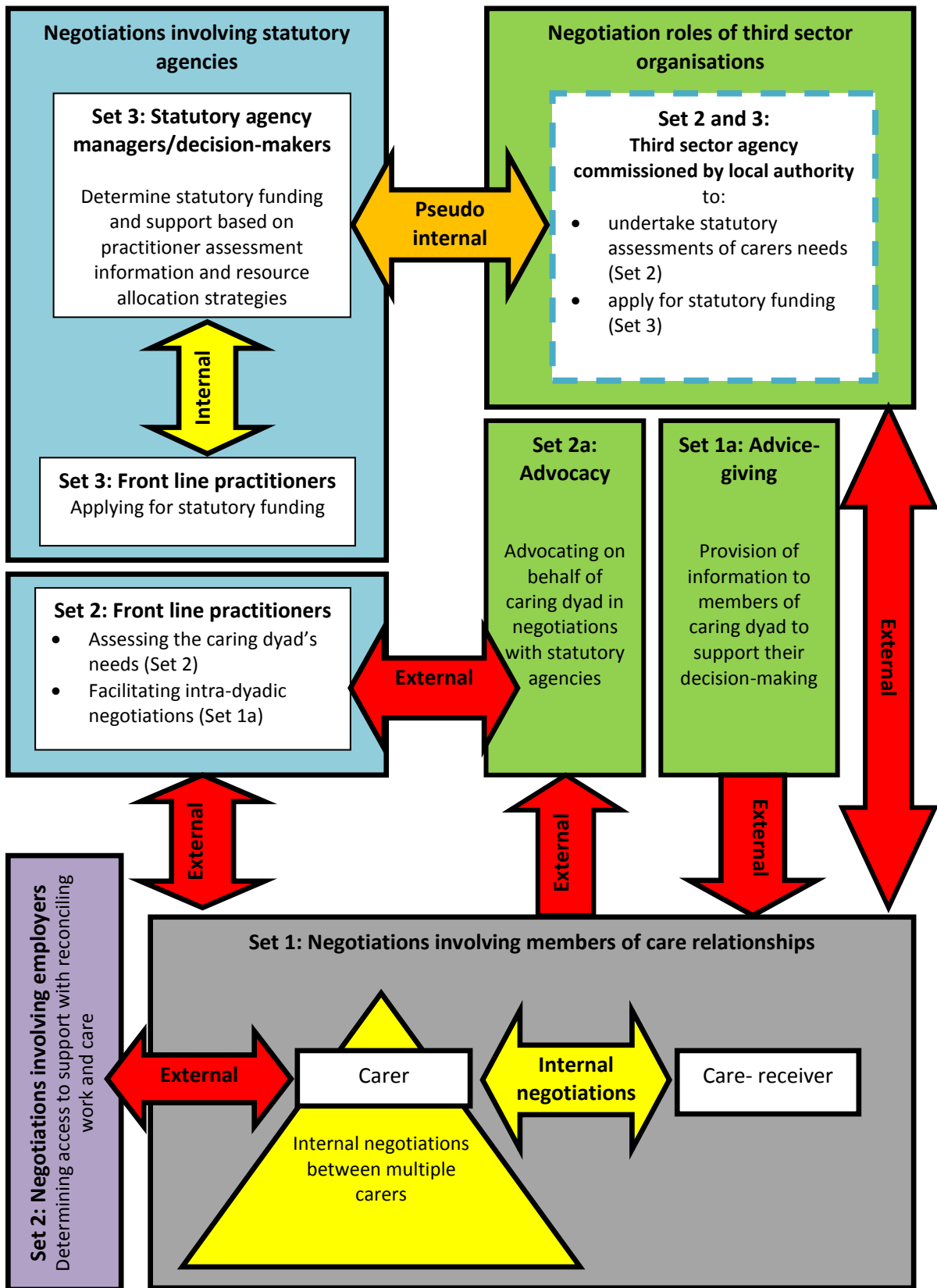
<sup>148</sup> Data relating to 2012-2013.

who on account of infirmity, mental incapacity, literacy, language or personality may lack the skills, knowledge, ability, self-assurance or capacity required to gain awareness of their potential rights and articulate their needs and wishes in a resolute way with statutory agencies. Consequently, more vulnerable groups may experience greater access difficulties and receive less adequate levels of statutory protection against the care-related risks they face than better educated and more able groups. This illustrates how personal attributes and characteristics can augment the inconsistency of statutory support outputs, and how institutional structures, processes and practitioners can potentially maintain the risks that some of the most vulnerable risk-bearers experience.

### **8.3 Negotiation processes affecting access to statutory protection**

The caring dyad's access to statutory protection is significantly affected by the complex chains of negotiations which occur within the institutional processes of the care policy environment. Figure 35 illustrates the diverse range of negotiations, consisting of internal and external negotiations, between different sets of actors, at different stages of the institutional process. Internal negotiations take place within pre-existing relationships, such as between members of a care relationship (Set 1), and between statutory agency practitioners and managers during the resource allocation decision-making process (Set 3). External negotiations take place between the caring dyad and the representatives of institutional providers of statutory support, such as statutory agency practitioners and employer organisations (Set 2). Third sector workers may intervene within both types of negotiations: by providing advice to individual carers or care-receivers to assist their internal decision-making (Set 1a); or advocating on behalf of the caring dyad in their external negotiations with statutory agencies (Set 2a). In LA2 they also undertake a statutory assessment role (Set 2). Each set of negotiations can have implications for the caring dyad being able to proceed along the ensuing negotiations within the chain.

Figure 35: Sets of negotiations between actors in the care policy environment



Each set of negotiation processes will be analysed in turn in order to expose the ways in which these processes can have significant impacts on the statutory outputs of the caring dyad and the extent to which their care-related risks are protected by the state. This analysis examines how these negotiations are influenced by inter-relational factors, the personal attributes of actors and the different modes of negotiation they adopt according to the role they seek to play, as well as institutional factors. It also exposes the adversarial atmosphere which infuses the overarching policy terrain which can produce risks by creating a demanding and antagonistic environment for actors to operate within.

### **8.3.1 Set 1: Internal negotiations involving members of the care relationship**

Set 1 negotiations take place between members of the caring dyad and where applicable the wider care relationship network. These internal negotiations are required to take place due to the inter-related nature of care. For example, as noted previously, much of the statutory care support that can help informal carers to reduce their care-related poverty and welfare risks requires the care-receiver to consent to receiving substitute care services. Where members of the caring dyad have disparate needs and wishes in relation to accessing statutory support these internal negotiations have the potential to produce inter-relational conflict and resentment. For example, some interviewees had experienced statutory support services such as respite care (L1LAP1) and domiciliary care (L2TS1M1) being refused by the care-receiver despite this being detrimental to the carer's wellbeing due to leaving them unsupported in their caring role and without access to a break. Furthermore if replacement care is not provided informal carers may be prevented from accessing support with managing their own welfare needs, such as counselling services, carer training sessions and health care appointments (L2TS1M2). The potential for these internal negotiations to create or compound existing relational difficulties, may also inhibit carers from feeling able to publically acknowledge the difficulties they are experiencing during a social services assessment visit (L1LAM3),

*'...you have to be very careful questioning the cared for and the carer because it is so easy for the cared for to say 'Oh my daughter does it all'.... but when you actually query with the daughter, the daughter might say 'Oh yes I do, but, oh gosh it's so difficult'....but....getting them, very honestly to express that, sometimes that can be very difficult' (L2LAM1).*

However, withholding information on account of the negative ramifications that a more explicit disclosure could have on the caring dyad's relationship, will ensure that the carer's risks are not addressed. For it can undermine an accurate assessment of the situation being conducted, resulting in a lack of appropriate support and protection being provided to the care relationship.

The design of institutional processes and regulations can enhance the necessity for these dyadic negotiations to take place and also exacerbate the potential for intra-dyadic conflict and relational tensions to arise. As noted in Chapter 7, carers' derived rights to statutory support in the cash benefits domain in particular can make them reliant on the care-receiver agreeing to claim their own form of statutory entitlement, such as AA, before they can claim statutory protection in their own right. This reinforces the care-receiver's power within the care relationship, particularly in the case of Carers Allowance where the application form requires the care-receiver's written consent as proof that the carer's claim is legitimate. Policy regulations can also subject members of the caring dyad to mutually exclusive statutory entitlements and risk-shifting, whereby institutional responses offer protection to one member against the risks they face whilst simultaneously generating or maintaining risks for the other member. This can exacerbate the risk of intra-dyadic conflict arising. For example, local authority financial charging and service categorisation policies can result in the statutory support which protects the carer against the welfare risks they face simultaneously creating financial risks for the care-receiver in the form of service charges. This risk-shifting may result in the carer's wish for support being overruled by the care-receiver if they refuse to pay for the necessary statutory support. Practitioners had experienced this occurring in relation to the provision of respite care services (L3LAP1), and carer break services,

*'If a daughter wanted to go out on a regular basis....now she has got to ask her father to add it to his package of care and pay an extra £48 for 3 hours [sitting service].....people have stopped having support because of that....' (L2TS1M2).*

In LA2 the re-categorisation of sitting services as a chargeable care-receivers service rather than a free carers service, was considered to have made it necessary for carers to be more explicit about disclosing the negative impact that the caring role is having on their lives in an attempt to persuade the care-receiver to accept and pay for this statutory support (L2TS1M1). A further example of risk-shifting incurred by institutional design exists in the cash benefits domain, where Severe Disability Premium (SDP) and Carers Allowance are purposively designed as mutually exclusive benefits.<sup>149</sup> Consequently, internal negotiations are required to determine which member is prepared to forego a form of benefit income,<sup>150</sup> and the additional forms of protection that their own individual entitlement would bring.<sup>151</sup> This required 'choice' has the potential to affect the quality of the caring

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<sup>149</sup> See Figures 30 and 31 in Chapter 7. The SDP is intended to help care-receivers with care costs and is considered to be an alternative to CA (BDWPM1).

<sup>150</sup> SDP and Carer's Allowance are worth £58.20 and £58.45 respectively.

<sup>151</sup> SDP can increase a care-receiver's basic personal allowance to £200.90 per week which increases their ability to access means-tested Guarantee Pension Credit and passported benefits (see CR8a). Meanwhile, CA provides carers with automatic access to (Class 1) National Insurance Contributions with which to build their

dyad's social relations due to the current and extended financial and welfare implications this decision can have for either member. The design of the CA regulations, which permit only one carer per care-receiver to claim this form of statutory protection (Directgov, 2012i), can create similar risk-shifting issues and entitlement tensions across the wider care relationship network. Consequently, this necessitates internal negotiations to take place between all involved carers in order to determine whose risks warrant statutory protection and whose will remain unprotected or partially protected via a lesser entitlement such as Carers Credits.

The statutory support choice of the care-receiver can also generate additional risks for the carer. If a care-receiver wants to receive a direct payment in lieu of direct service provision arranged by the local authority, this often requires dyadic negotiations to take place. This is because the informal carer may need to support the care-receiver with the considerable management, financial and employee responsibilities that this care delivery option entails (L1TS1M/L2LAP2). Some carers were noted to struggle with this management role,<sup>152</sup> but often concede to taking it on because they,

*'...feel that it is the only way forward to give them the flexibility that they would wish for themselves and for the cared for person' (L2LAM1).*

Intra-dyadic conflict can also be generated in cases where the direct payment is used to formally employ the informal carer to provide the care-receiver's care. This blurring of roles can generate welfare-related risks for the carer by undermining their ability to take an adequate break from their caring role.<sup>153</sup> This can be exacerbated by their formal employment status undermining their entitlement to statutory support such as carers assessments and carer services (L2LAM2/L1LAM2).

The outcome of the carer's external negotiations with their employer could also have negative implications for their relationship with the care-receiver. Due to the weakness of their statutory employment rights, carers may feel compelled to tailor their flexible working request to the needs of the business by '....put[ting] forward a case which is more likely to be accepted by the line manager' (ETSM1). However, constructing their request around the needs of their employer rather than the actual requirements of the care relationship may generate welfare and time poverty risks for the carer as they struggle to reconcile their working and caring responsibilities. This in turn could create stress-related conflict between the caring dyad due to neither member's needs being adequately addressed and met.

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entitlement to all contributory benefits. It also provides automatic protection against having to re-enter the labour market (L1TS2M).

<sup>152</sup> '....the daughter said I've got enough to do without doing all this as well' (L1LAP3).

<sup>153</sup> 'How does that person get their own support, when do they switch off' (L2LAM1).

### **8.3.1.2 Set 1a: Involvement of external actors in facilitating dyadic negotiations**

The caring dyad may rely on external actors facilitating their dyadic negotiations, either through the provision of advice and information, or through their active involvement in attempting to resolve dyadic disagreements. This facilitation role may be undertaken by a range of statutory and third sector actors, whose level of involvement in these internal negotiations may vary. In the case of the DWP, benefit assessors do not actively engage in dyadic negotiations. If conflict arises between the caring dyad or multiple carers on account of mutually exclusive cash benefit rules, the DWP response is to either ‘...offer advice on what entitlements will be’ but ‘I would say it is up to the carer and the parent to decide...’ (BDWPM1); or else unilaterally determine which carer can claim CA (Child Poverty Action Group, 2012). Third sector workers play a more proactive role in facilitating dyadic negotiations. However, the level of impartiality of their advice within these negotiations can vary considerably depending on their organisation’s affiliation. For example, one advisor from a generic organisation stated that they would treat the caring dyad as a unit and provide impartial advice,

*‘This is where as a benefits advisor you actually look at which is more beneficial...you will get some situations where one option or another can be much more lucrative’ (BTSP1).*

Meanwhile, an advisor from a specialist organisation considered themselves to be representing the interests of the carer,

*‘...[O]bviously our leaning is towards the carer so we would not deliberately deprive a service user but we would point out the advantages for the carer of claiming Carers Allowance’ (L1TS2M).*

Consequently advisors may provide biased advice which augments the statutory protection of one member at the other’s expense, thereby contributing to risk-shifting across the caring dyad. Meanwhile, front line practitioners in the care services domain were also noted to intervene in dyadic disputes in cases where either the carer is deemed to be undermining the care-receiver’s independence by ‘...doing things for them....they are perfectly capable of doing themselves’, or where the care-receiver is expecting too much of the carer (L1LAM3).

### **8.3.2 Set 2: External negotiations between the caring dyad and statutory agency practitioners**

Set 2 negotiations occur between the members of the caring dyad and front line practitioners who administer institutional processes such as assessment and care and support planning. These external negotiations are dominated by practitioners who determine how members of the caring

dyad are treated by statutory agencies and whether risk-bearers will gain access to statutory support to protect them against the care-related risks they experience.

### **8.3.2.1 Personal attributes and skills of practitioners affecting statutory outputs**

The professional skills, knowledge, personal attributes and experiences of front line practitioners involved in assessment negotiations can have a significant bearing on the caring dyad's statutory support outputs. Practitioners determine the caring dyad's eligibility to support based on the assessment information they obtain. Consequently, many local authority practitioners highlighted the importance of conducting detailed, professional assessments of the caring dyad's situation in order to ensure that their needs are identified as accurately as possible. This entailed practitioners adapting the style of assessment to meet the individual's needs;<sup>154</sup> conducting a comprehensive assessment; and undertaking an in-depth exploration of the presenting issues by locating the right trigger to elicit a more candid response and '....draw out the most information' (L3LAP1/ L1LAP3). For carers were often noted to begin the assessment by saying,

*'I'm fine', '.....but....actually that's out of embarrassment, out of duty....that's why assessment isn't a tick list....it's actually the whole skill of assessment, observation....to pick out what is underneath' (L1LAM1).*

Several practitioners considered their own personal experiences of providing informal care to have enhanced the quality of their assessment skills: providing them with an improved ability to identify a carer within a given situation; with their personal insight enabling them to conduct a more thorough and sensitive assessment.

*'Because I am experiencing it myself...I understand....the strain that it puts you under and how stressful it can be at times....I'm probably more likely to offer someone a carer's assessment than probably some of my colleagues' (L1LAP2);*

*'....unless you have done it, you haven't got a clue. I mean I didn't have a clue before I started [caring]. You just go oh yes it must be hard. But....I know now if somebody says I'm fed up, I know that means more than I'm fed up. Sometimes it's I'm not coping, or I can't do it anymore....And I find that I....can say the right things to them and then they come out with it, very often it is the guilt....I should be able to do this' (L1LAP3).*

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<sup>154</sup> A thorough assessment was noted to take an hour and a half to complete which can be '....difficult for someone to sustain, particularly a stressed carer' 'So what I do, and I think that comes from experience, you end up having a conversation and....while we are talking I will find the right page and start writing' (L3LAP1).



The personal attributes and knowledge of practitioners could also affect the treatment of informal carers by statutory agencies and their statutory support outputs. In the JCP domain, the ‘kindness and discretion’ of front line practitioners was considered to have a significant bearing on the extent to which carers are protected from benefit sanctions (BTSP1). For example, one interviewee considered there to be no excuse for carers failing to actively seek work in the internet age,

*‘I don’t really think that anybody has really got any excuse because they are never caring 24 hours a day’ (L2JCP1).*

In contrast another commented that they actively seek to protect carers by providing them with advice about how to word their Job Seekers Agreement; offering them prompts during their review meetings;<sup>155</sup> and advising them of alternative options,

*‘.....well can you not try and do 35 hours [of care] and claim Carer’s Allowance? You can still look for work but without the pressure’ (L1JCP1).*

Practitioners may also inadvertently deny individuals access to particular types of support on account of their own ignorance. For example, JSA administrators were considered to be less well informed than IS administrators about the regulations which permit carers to apply more generous restrictions to their Job Seekers Agreement (L2JCP1/L1JCP1). Meanwhile generic local authority practitioners in LA2 acknowledged having less extensive and up to date knowledge of both statutory and non-statutory support for carers than specialist carer assessors (L2LAP1/L2LAP2). This was also reflected in LA1 data where the specialist worker had greater awareness of the training courses for carers and the additional sitting service hours that could be provided to facilitate their participation; the telecare pilot project providing free assistive technology to support carers; and the council’s leisure discount scheme for carers (L1LAM3).

### **8.3.2.2 Practitioner roles affecting statutory support outputs**

The power imbalance contained within these external negotiations, and extent to which the caring dyad are helped or hindered from accessing statutory protection, can be mitigated (to some extent) or exacerbated by practitioners’ perceptions of their role within these negotiation processes. Some practitioners adopt a gate-keeping role and restrict the caring dyad’s access to statutory resources by controlling the information they provide during the assessment process about the types of statutory support that are available. Meanwhile other practitioners actively seek to promote the caring dyad’s awareness of the statutory support available and to provide them with access to this protection.

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<sup>155</sup> ‘You have been looking [for work].....haven’t you’

Practitioners who adopted a gate-keeping stance did so for a number of reasons. For some the wish to protect statutory resources predominated. One local authority practitioner admitted withholding information about statutory support services from care relationships if they believed alternative non-statutory resources to be available,

*'...because at the end of the day.....we still have a responsibility for the public purse and you know it's not a bottomless pit.....and while you are giving everything to one person you can't always give to the next.... so you've got to weigh up needs....' (L2LAP2).*

Other practitioners withheld information on account of their own personal concerns about poor service quality and value for money (L1LAP1); the lack of perceived effectiveness of specific types of support such as telecare (L1LAP3/L1LAP1/L1LAP2); the administrative complexity and time-consuming process of setting up a direct payment and negative assumptions about the ability of older people to manage them successfully (L1LAP1/L1LAP3/L1LAP2). Practitioner perceptions about the paucity of the support on offer and their assumptions about the usefulness of particular types of support for the caring dyad also affected the disclosure of information,

*'...[it's] really hard to say give somebody £200 for a year's worth of massage treatments and justify in your head....actually how it's going to be of any use' (L2TS1M1);*

*'.....most people that we go and see we wouldn't even mention the [carers' personal] budget to them if we didn't think that it was something they needed' (L2TS1M1);*

*'I think most of us would go out with a range of options available.....and you try and pitch it at what you think they will accept...' (L3LAP1).*

In addition, one JCP practitioner considered that it was not their role to share information about resources with individuals,

*'I mean I don't offer flexible support fund, I don't say do you need any clothes, no I'm sorry I don't, if they need them they need to tell me. I'm not going to guess' (L2JCP1).*

These comments highlight the significant power that practitioners hold over these negotiation outcomes. Moreover, basing decisions on their own assumptions about service effectiveness and the requirements of the caring dyad instead of providing the caring dyad with the opportunity to make their own informed decisions and choices, exacerbates the unilateral nature of these types of external negotiations. Meanwhile, some practitioners considered it possible to mitigate the power imbalance contained within these negotiations by adopting a more proactive way of working. One local authority practitioner noted sending information out about the range of support options that are available prior to the assessment visit in order to support individuals' decision-making and enhance their awareness of how 'certain [assessment] questions will guide a social worker down a

resource path' (L3LAP1). Their intention was for the care planning process to be conducted '.....almost like a negotiated agreement' between the assessor and caring dyad. Similarly one JCP practitioner also noted explicitly asking carers about whether they needed the specific types of employment support available (L1JCP1).

Third sector actors may also engage in Set 2 negotiations, either as independent advocates, or as front-line assessors in their own right. In terms of the former role, third sector workers may act to bolster the ability of the caring dyad to access statutory protection by advocating on their behalf during these external negotiations. Third sector workers described these negotiations with statutory agencies to be adversarial in nature because they had to challenge statutory decision-making in order to ensure that '....services are doing what they should be doing' (L1TS2M/L2TS1M2). This necessitated their intervention within different negotiation processes and across different policy domains in order to support the caring dyad to make benefit applications and appeal refused claims; debate the interpretation of benefit guidelines with JCP and Benefits Agency practitioners; and challenge local authority decisions affecting carers' access to carers assessments and support services (L1TS2M). The tactics they employed to advocate for the caring dyad ranged from: directly challenging the legality of statutory agency decisions and practitioners' erroneous interpretation of the regulations,

*'They are kind of just going if you are not getting Carers Allowance then you have got to sign on so we are kind of ignoring your caring responsibilities' '.....and I say you need to read your guidelines then' (BTSP1);*

to attempting to exploit ambiguous regulations to the caring dyad's advantage. For example, one interviewee considered how they would support the part-time carer (CR3) to apply for Income Support noting,

*'....if it is always 16 hours a week, I mean it is regular isn't it, it's the substantial that is the issue' (BTSP1).*

The adversarial nature of these negotiations can contribute to tensions emerging in the social relations of third sector organisations and statutory agencies which can undermine trust at an organisational level. For example, third sector workers who described themselves as having to '....battle...and....fight' statutory agencies to enable the caring dyad to access their statutory entitlements, raised concerns that this could place them in '.....a difficult situation because we are funded by social services' (L1TS2M). Similar organisational tensions could also be generated at a strategic level due to third sector organisations lobbying local authorities to provide more adequate support for carers,

*'.....that is constantly difficult because if you are trying to lobby....but at the same time you are being funded, so you are biting the hand that feeds you' (NTSPR).*

Meanwhile in LA2, where a third sector organisation was commissioned by the local authority to carry out the statutory carers assessment function on their behalf, these third sector assessors continued to perceive their role to be one of advocating for carers,

*'...we are not social services and we will come down on the side of the carer every time....'*  
*(L2TS1M2).*

They did not seek to conform to *'...the council's idea...that we would just go in do the [carer's] assessment and move onto the next one...'* (L2TS1M1). Consequently, these workers predominantly adopted an information-sharing rather than gate-keeping approach to their assessment negotiations with the caring dyad,

*'.....we're not tied by the constraints that the social workers are tied to. So we can give the carer all the options whereas if [the social worker's] been told they've got no money....then they might go out and only give them part of the information' (L2TS1M1).*

They would also actively challenge the decisions made by local authority practitioners engaged in the community care assessment process,

*'.....in order to make the care-receiver's support package more conducive to supporting the needs of their carer' (L2TS1M1).*

However, this advocacy approach was not endorsed by the local authority who considered that the commissioned status of the third sector agency made them a quasi-internal actor within the statutory system. Consequently, they expected third sector assessors to show a greater affiliation to local authority practices. The dissonance between the perceptions and expectations of the local authority and the third sector agency about their assessment role could generate tensions between both parties.

*'Issues can arise where you have got workers carrying out that commissioned work but their identity is so ingrained with the third sector provider that....they may not always represent the local authority in the best light and they may not appreciate their responsibilities as indirect employees of the local authority' (L2LAM2).*

### **8.3.3 Set 3: Internal negotiations between practitioners and managers within statutory agencies**

#### **8.3.3.1 Marginalisation of caring dyad and practitioners within negotiation processes**

Set 3 negotiations are internal negotiations which take place within statutory agencies between the front line practitioners who have assessed the caring dyad's needs and the managers who oversee the resource allocation process. This analysis exposes the opacity of these internal negotiation processes. For these negotiations are generally conducted without the direct involvement or participation of the caring dyad,<sup>156</sup> even though it is these negotiations which ultimately determine whether, and how much, statutory protection they will receive to address their care-related risks.<sup>157</sup> Their exclusion from this stage of the institutional process highlights the importance of individuals having accurately presented their situation during their assessment meeting with front line practitioners. It also exposes how the members of the caring dyad are subsequently dependent on those practitioners accurately interpreting their needs and presenting their case to management representatives in a way which truly represents their situation and justifies their request for statutory support. However, often the practitioners themselves do not participate directly in these internal resource allocation decision-making processes either. The caring dyad's inability to directly or indirectly influence this key negotiation process can therefore contribute to decisions being made which are disconnected from individuals' expressed and assessed needs and may therefore not address the risks which they face.

Where practitioners can engage in face to face negotiations with managers during resource allocation processes this can provide them with the opportunity to actively promote the caring dyad's application for statutory support. For example, one JCP practitioner commented in relation to accessing financial support from the Flexible Support Fund to purchase interview clothing for carers,

*'...I do think that if an advisor....really felt that it was important and necessary it would be down to our negotiating skills to persuade the manager to allow it....' (L2JCP1).*

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<sup>156</sup> In LA2 in exceptional circumstances the resource allocation panel would 'perhaps bring the person in and speak to that person' if members had concerns about the risks relating to a particular individual's funding application (L2LAM1).

<sup>157</sup> This issue is also relevant to JCP decision-making processes which determine whether benefit recipients are sanctioned. One practitioner noted 'We don't make the decisions locally, they are sent away for specialist Decision Makers to consider. The customer is able to give their reasons/excuses, before the paperwork is sent off' (L2JCP1).

However, in the care services domain written applications form the key mode through which practitioners convey the assessed needs and statutory support requirements of the caring dyad to managers in resource allocation panels,

*'The main thing to do is to write your background information form to panel to get your services and they can make their minds up' (L1LAP1).*

The ability of practitioners to influence these internal negotiations can therefore be significantly restricted. For although the only knowledge that local authority panel members have of the caring dyad's circumstances, needs and wishes emanate from practitioners' written funding applications, examples were provided of resource allocation decisions being based on panel members' own assumptions about how an individual's needs could best be met. For example, carers' applications for personal budgets to specifically purchase a holiday; and a swimming membership at a private club were rejected by panel members in lieu of alternative offers. In the case of the holiday the panel members had wanted to,

*'.....look at what other services they can provide to ease your load, but as I said sometimes you just need to....get away. And they are saying yes but you've still got to come back. Yes, but you come back refreshed. But they don't seem to get that now' (L1LAP3).*

In relation to the latter, the practitioner subsequently challenged the panel's decision stating,

*'....actually **we** have assessed this....firstly she doesn't want to go to a family-orientated sports facility, she's an older lady, she wants to be somewhere where she's got easier access, not so much noise, she's used to that kind of lifestyle, she would rather be there....' (L2TS1M1).*

Furthermore, practitioners stated that panel members were increasingly basing their funding decisions on the expectation that family members,

*'should provide some support to the older person....whether or not you've had that discussion with the daughter' 'I mean they are expecting families to be carers and not all families want to be. Its budget cuts, that's all it is, its budgetary' (L1LAP2).*

Meanwhile in LA1 panel member's decision-making was also noted to be influenced by local authority brokerage team administrators who operate as resource finders. Practitioners described how these unqualified workers,

*'.....may reduce what I am asking for.....They will say 'well actually it doesn't take that long to do that, you can have this [instead]' (L1LAP1).*

This type of rationing device could lead to unrealistic and potentially unsafe support packages being proposed,

*'...what they are saying [is] 15 minutes for hoisting. Well you can't do it' (L1LAP3).*

These examples illustrate how the caring dyad's statutory support outputs could be substantially influenced by actors with no direct knowledge of the caring dyad. This permits decision-making within resource allocation processes to be dominated by consideration of institutional factors such as the management of budgets and resources rather than the caring dyad's wellbeing and wishes. Consequently this can contribute towards the caring dyad's choices being undermined and inadequate statutory protection being provided against their care-related risks.

### **8.3.3.2 Impacts of practitioner and manager roles and strategies**

Although these internal negotiations take place between members of the same organisation they remain subject to inter-personal conflict due to practitioners and managers using a variety of competing strategies to either promote the ability of the caring dyad to access statutory support or protect state resources respectively. This can provoke antagonism and conflict between them. Practitioners described these internal resource allocation negotiations as 'battles' and used terms such as 'fight' and 'argue' to describe their interactions with panel members as they attempt to get their funding applications accepted and authorised by managers (L1LAP1/L2TS1M1). For example, one practitioner who had applied for a direct payment to enable a care-receiver to purchase care from a preferred agency stated,

*'.....[P]anel are making it so difficult to get any of these sort of payments through, although I just recently got 2 through.....but it took a lot of fighting and arguing....I had such a battle with that and it took me a hell of a long time' (L1LAP2).*

Practitioners frequently described advocating for the caring dyad during these negotiations processes,

*'I'm happy to argue, justify, be assertive for what I feel that person needs.....I'm really happy to act as their advocate in effect' (L3LAP1);*

*'If someone needs something.....I will do my best to get it for them' (L1LAP1).*

Moreover, 'austerity' related budget cuts were considered to be making it '....harder to get anything through panel' (L1LAP2), thereby making advocacy even more essential,

*'....At one time you could ask for 30 minutes for a lunch call....Now they are cutting it down to 15 minutes. You have to plead to get meal preparation' (L1LAP1).*

However, one manager considered it to be the practitioner's role to gate-keep statutory resources and manage public expectations rather than advocating and promoting individual's wishes. They acknowledged that practitioners may,

*'.....find it difficult to say no, because they are caught up in the emotion of the situation, you know 'oh I want to do something to support them' (L1LAM1).*

However practitioners were deemed to have a responsibility to inform individuals that although local authorities have a,

*'....statutory duty to meet your needs....we've also got the right to say we will meet that in the most cost effective way possible' (L2LAM1/L1LAM1).*

Meanwhile, managers who operated as panel members perceived themselves to have a gate-keeping role within these internal negotiations (L1LAM1). This involved assessing the appropriateness of practitioner's funding applications according to whether,

*'.....the need is an eligible one.....your choice of support is going to enable you to meet the need....and it's going to be cost effective....' (L2LAM1).*

Conflict could be generated during this process due to differential interpretations of eligibility thresholds being applied by different sets of actors (L3LAP1) as noted by one practitioner,

*'I know it's supposed to be critical and substantial but I don't know what they [panel] class as critical and substantial' (L1LAP3).*

Practitioners also expressed resentment at how their professional assessments could be over-ridden by panel,

*'I've.....gone out and assessed a situation as being substantial....they shouldn't be questioning our findings because that's the assessors view, they've been in the house' (L2TS1M1).*

Moreover, the current financial climate was augmenting the panel's performance management function.

*'I think like most local authorities the actual budget we have is....very tight.....and so we are having to manage it differently....I think what you could possibly have gained authorisation for a few years ago....you wouldn't get through now, you'd be challenged more' (L1LAM1).*

Practitioners were being increasingly challenged by panel to '....sharpen up their assessment....' and to present a 'proportionate response' to meet an individual's assessed needs (L1LAM1). This increased scrutiny often required funding applications to undergo more than one iteration of the panel process as panel members either seek further clarification (L2LAM1); or expect practitioners to



explore particular options ‘...before we commit the funded support to it’ (L1LAM1); or only agree to short-term funding,

*‘...panel say you can only have it for so long, then you have to back to panel’ (L1LAP1).*

These perceived ‘delaying tactics’ (L1LAP1) could contribute to practitioner frustration due to it extending the length of time it would take to get any statutory support agreed and implemented.

*‘You do your assessment that should be it really, but you have to go and talk to brokers, see what they suggest...Then it goes to panel and gets knocked back, you put it back to panel, it gets knocked back....So by the time you’ve done all that you’re thinking why did I even bother going out?....’ (L1LAP3).*

This in turn could generate tensions between practitioners and the members of the caring dyad who are left waiting for the statutory support and protection they require to address their care-related risks.

During these internal negotiations a variety of strategies may be applied by both sets of actors to further their own objectives and mitigate the effects of each other’s. The overarching strategy of practitioners was to present a ‘sales pitch’ to panel members which was most likely to garner their agreement. However, the tactics applied could vary as to whether practitioner’s tailored their funding applications to the caring dyad’s needs, or to institutional budgets and resources. For example, in some cases practitioners down-rated their funding requests according to the amount of statutory support previously agreed by panel rather than requesting what they actually considered the individual to need. This use of precedents was applied to day care requests for high need (Tier 1) care-receivers, with several practitioners restricting their request to only one or two days per week on the presumption that panel members would not agree to provide more (L1LAP3/L1LAP2),

*‘...you couldn’t go to panel and say I want five days day care for this lady because this daughter’s not coping....in this climate.....we could look at day care perhaps one day per week.....’ (L1LAP1).*

However, practitioners were more likely to apply a variety of covert tactics to increase the likelihood of panel authorising service levels to meet an individual’s assessed needs. This included ‘up-rating’ the amount of domiciliary care they considered service users to require in order to access what they actually need,

*‘I’d go for....an hour in the morning which I probably wouldn’t get....they’d probably give me 45 minutes....whereas I figured if I asked for 45 minutes I’d get 30.....’ (L1LAP2);*

And *'find[ing]...ways of wording things so that we've told them what it is that we are asking for but we haven't quite told them what it is [specifically]....'* (L2TS1M1).

Some practitioners highlighted particular case details which they considered would 'sell' the funding request to panel. In the case of CR8a they noted,

*'We could probably get 3 calls per day....because the carer's at work....so they can't be there at lunch time.....If you were trying to sell it to panel you would sell it that way'* (L1LAP1).

Others attempted to pre-empt panel's cost-cutting strategies and protect families by highlighting the risks associated with the assumption that family members should provide care,

*'...if you're expecting the daughter to do that it will probably break down. And that's what you've got to keep saying that it will probably break down...'* (L1LAP2).

However, not all practitioners considered adapting their requests to promote panel authorisation,

*'...I'm not compromising my assessment just to fit in with panel. It's up to them to make that decision, if they are saying no and it all goes wrong, that's what they have said'* (L1LAP3).

Meanwhile, panel members applied their own range of strategies to achieving their overarching objective of protecting local authority resources. These strategies were primarily intended to counteract what managers presumed to be practitioners' automatic response to an assessed need '*...being OK what [local authority] services can we put in...'* (L1LAM1). Panel members noted recommending a range of alternative sources of statutory and non-statutory services and funding which constitute zero cost options for the local authority. For example, applying for NHS continuing health care funding was considered 'a matter of social justice' for all high need Tier 1 care-receivers (L1LAM1) which could, if successful, protect both individual and local authority resources. Low need Tier 3 care-receivers would be advised to claim AA to cover the cost of their care privately (L1LAM1). Meanwhile community resources were recommended to address social inclusion needs in lieu of local authority day care being provided.<sup>158</sup> Panel members also acknowledged that 'there would be an exploration' (L2LAM1) of what support an individual's family network could provide or maintain,

*'...If people were saying I can't do it anymore, it might be OK is that all the week, is that part of the week, are you still able to carry on doing weekends'* (L1LAM1).

This highlights how instead of alleviating informal carers' caring responsibilities and care-related risks through the provision of statutory support, panel decisions can instead constitute obligations

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<sup>158</sup> For example, using a religious community group to 'support someone to get to church' or accessing community luncheon clubs.

on informal carers to continue to undertake caring work. This in turn could generate dilemmas for practitioners. One practitioner stated,

*'I'm not going to ring around sons and daughters and say 'well actually it's your mum, she needs a wash....You should be doing it get on with it...it's good if families will support.....but I don't assume ever that they will do it. If they are working you can't expect them to do it. They've got their own lives to lead. They are individuals in their own right' (L1LAP1).*

Meanwhile, where panel members agreed to provide local authority resources to meet an individual's assessed need they would authorise lower cost alternatives such as telecare, in lieu of the more expensive domiciliary care options requested by practitioners (L1LAM1). Individuals could still opt for a more expensive or preferred service option if they were prepared to pay a private 'top up' (L1LAM1). These examples illustrate how a substantial number of these strategies shift the financial risks of care provision away from the state and back onto individuals and families, thereby maintaining or exacerbating the caring dyad's care-related risks.

## **8.4 Conclusion**

This chapter reveals that even where statutory care-related support is available, the actors and the negotiation processes contained within the care policy environment can significantly affect the caring dyad's ability to access this existing statutory protection. Consequently this can exacerbate unequal statutory outputs occurring across care relationship types. Moreover, institutional and inter-personal factors can be seen to maintain and in some cases exacerbate the care-related risks experienced by the caring dyad, or produce additional risks. Not least due to the intra-dyadic tensions and inter-relational conflicts which these negotiation processes can generate ensuring that the overarching policy terrain can be difficult and demanding for all concerned to engage in. The resulting adversarial atmosphere requires all actors to invest considerable amounts of emotional labour, time and energy into engaging within the care policy environment which illustrates how the system itself produces welfare-related risks.

This chapter's findings reflect key features which emerged from the previous analysis chapters. Firstly, in Chapter 6 the analysis of the eligibility criteria demonstrated how the caring dyad's personal characteristics could significantly affect which individuals are permitted access to statutory support. In turn this chapter reveals how an individual's characteristics can also significantly affect their own systemic knowledge and awareness of their potential entitlements and the level of articulacy with which they explain and assert themselves within external negotiation processes. This can exacerbate the existence of unequal statutory outputs across care relationships on account of

people's health status, class and educational status and English language abilities. Secondly, in Chapter 7 the weakness of the informal carer's position within institutional processes and the contingent nature of many carers' entitlements on the care-receiver were revealed. This chapter exposes how the carer's ability to influence negotiation outcomes is constrained by unequal power relations and their weak positioning or absence within negotiation processes. Moreover, their statutory outputs remain highly contingent upon their negotiations with the care-receiver and the personal attributes and professional agendas of the actors involved in assessing their needs and making resource allocation decisions. Thirdly, the significant influence that individual actors have over whether the caring dyad's care-related risks receive statutory protection increases the opacity and unpredictability of the institutional terrain. Although practitioner discretion is institutionally permitted, it is augmented by actors intentionally and unintentionally subverting institutional procedures and statutory intentions within negotiation processes. This in turn undermines the caring dyad's knowledge and understanding of the policy environment and realisation of their potential entitlements.

This chapter's findings help to reiterate and consolidate the key findings generated in the previous analysis chapters about the state's treatment of informal care. It continues to expose how the way in which institutional processes function undermines the ability of the state providing universalist protection to informal carers and the older people they care for. This reiterates the argument that the state does not treat informal care as a social risk. Moreover, it also offers further illustrative examples of how, despite agency and practitioner discretion and personalisation approaches being permitted and actively promoted by the state, care policy arrangements, processes and actors can actively undermine the ability of the caring dyad having choice and flexibility over how their care-related risks are addressed. In summary, the current care policy system does not provide risk-bearers with protection and does not give risk-bearers choice.

## Chapter 9: Discussion

### 9.1 Introduction

This thesis set out to explore the extent to which the English state treats informal care as a social risk by answering the following research questions:

- How do welfare state care policies treat the care-related risks of different types of informal care-givers and the older people they care for in England?
- How far and in what ways do these policies recognise and treat informal care as a social risk which requires public support and protection?

This chapter discusses the key research findings pertaining to these research questions and sets these findings in the context of the existing literature. Policy recommendations are incorporated throughout the chapter. These provide suggestions as to how the state could rectify the current deficiencies of the system in order to improve the functioning of the care policy environment and the statutory support outputs provided, and promote the state's treatment of informal care as a social risk.

This chapter is structured as follows. Sections 9.2 to 9.4 discuss the research findings pertaining to the social risk literature and care policy literature. Section 9.2 reveals how informal care is recognised by the English state as a social risk in the national carer strategies, however the analysis of the care policy system and statutory support outputs has exposed how informal care is not treated as a social risk in practice. Although certain types of informal carers receive some statutory protection against the care-related risks they face, carers' risks generally remain either fully or partially privatised through a variety of means. The gaps in statutory provision and the inadequacy of the support on offer, therefore maintain the primary risks associated with care-giving. The implications of this for carers from higher risk groups who are more likely to provide care, or are more vulnerable to experiencing care-related risks, will be re-examined here. Moreover, the findings also expose how the institutional arrangements contained within the care policy system produce secondary risks which can create, maintain or exacerbate the poverty and welfare risks experienced by the caring dyad. Section 9.3 discusses whether it is possible to talk about national statutory 'entitlements' for informal carers in the context of localism, practitioner discretion, and personalisation. Moreover, it considers the extent to which the level of inconsistency and variation these system and actor effects produce in the caring dyad's entitlements is problematic for care relationships and the treatment of informal care as a social risk. Section 9.4 reflects upon the

overarching treatment of informal care and informal carers by the state. It considers the unique position informal carers occupy in the English welfare state and their unique treatment by the state. It also explores how the factors which influence policy-making processes, including the claims-making of carers' organisations and social threats such as population ageing, have affected care policy development. Additional policy complexity, in the form of inconsistent policy trends, is also identified with recent policy developments showing the state to be retrenching and strengthening carers' rights concurrently. Finally, section 9.5 contemplates whether the overarching treatment of informal care in England adheres to the ethics of care principles set out in the feminist literature. This analysis considers the state's attentiveness, responsibility, and responsiveness towards informal care, and reflects upon how existing policies manage the inter-relational nature and diversity of care, and provide individuals with legitimate choices in relation to providing and receiving care. The conclusion is drawn that an ethics of care is not present within the policy system and that the English state does not value care as an activity nor those engaged in the activity of caring.

## **9.2 The recognition and treatment of informal care as a social risk in England**

### **9.2.1 The recognition of informal care as a social risk**

It is necessary to make the distinction between the recognition and treatment of informal care as a social risk and address both forms of state acknowledgement separately. In terms of the former it can be argued that the English state does recognise informal care as a social risk. The comprehensive analysis of the needs of informal carers undertaken in each of the carer strategies (Department of Health, 1999, 2008, 2010c) is testament to the fact that the state formally identifies and recognises informal care as a risk-based activity. For as noted previously in Chapter 4, the strategies recognise the diversity of carers and acknowledge the need for informal carers to be protected from the range of poverty and welfare risks they can face. The state is also considered to have a key, although not the sole, responsibility to provide support and protection to informal carers in their caring role, alongside the family, individuals, and wider society (Department of Health, 2008, p. 38). Furthermore, the carer strategies stipulate the types of public support successive governments have wanted different government departments and agencies to provide and develop for informal carers in order to better protect them against the risks they face. However, the strategies themselves contain no legal or compulsory requirements and were described by one interviewee as having 'no teeth' (NTSPR),

*'A strategy is only that, it is a strategy, how it is followed up within other organisations is very much for them', '...it is for each department to take forward its policy', 'it's for others to pick that up and run with it locally' (NGPR).*

Consequently, the combination of the fragmented and decentralised nature of the English welfare state's governance arrangements together with the strategies' statutory weakness, constrain their ability to drive forward the policy action required to improve how informal carers are supported by the English state. For individual government departments and local authorities retain control over deciding whether or not to embed the carer strategy recommendations within their existing policy frameworks and the design of the statutory support they provide. The carer strategies, therefore, occupy a peripheral and weak position within the overarching policy environment, thereby reflecting informal carers' own positioning within the system.

The ineffectiveness of the carer strategies to generate significant policy change is evidenced by my research findings which reveal how many of the key carer strategy recommendations have not been fulfilled. For example, service delivery remains un-coordinated and disaggregated rather than being integrated in a seamless way across individual agencies. This leaves informal carers to continue to have to piece together their support from many 'suppliers' who seem very often to be working against each other and against the carer (Department of Health, 2008, pp. 38, 44). In addition, the marginalised positioning of informal carers within the care policy system exposes how they remain '...not sufficiently high on the agenda of some organisations and in some service areas' (Department of Health, 1999, p. 15). Meanwhile, the inadequacy of the Carers Allowance and the need to radically reform it has been recognised in every carer strategy. However the Carers Allowance remains unchanged by the DWP to date. These examples illustrate how it is not enough for the state to recognise informal care as a social risk through its strategies if this does not produce policies and policy outputs which ensure that informal carers and their care-related risks are comprehensively supported and protected in practice. Undertaking this in-depth analysis of the construction and operation of the care policy system and its associated governance arrangements has revealed the actualisation of the carer strategy objectives to be unworkable. For the research findings show that they are consistently undermined by the systems and actor effects produced by the fragmented, opaque, inconsistent, and adversarial nature of existing institutional structures and processes.

### **9.2.2 The treatment of informal care as a social risk**

For a state to be considered to treat informal care as a social risk the following requirements would need to be met: all types of care relationships and care-related risks would need to be universally

recognised by the state; *and* these recognised risks and affected risk-bearers would need to be provided with adequate, predictable, and consistent, statutory protection. This study's detailed analysis of institutional structures and processes and the statutory support outputs of different types of care relationships clearly reveals that care-related risks and risk-bearers are subject to inconsistent statutory recognition and protection. Consequently, informal care cannot be said to be treated as a social risk by the English state in a number of ways. Firstly, there is an overarching lack of adequacy in the level of statutory protection provided to care relationships which leaves even the recognised risks of acknowledged risk-bearers only partially socialised. For example, non-working, full-time carers who provide over 35 hours of care per week are the key group of informal carers who are generally guaranteed to be considered eligible to access statutory protection. Even so, the level of statutory support that even these informal carers receive is not adequate enough to protect them against the care-related risks that they face. The Carers Allowance and the personal allowances set for low income carers, fall well below the Minimum Income Standard set by the JRF for ensuring that individuals are protected against poverty risks (Hirsch, 2011).<sup>159</sup> Meanwhile replacement care services, such as sitting services, day care and domiciliary care, are often provided at such minimal levels that they cannot effectively protect informal carers against welfare risks. In LA1 where the maximum level of sitting services provided amounted to 70 hours per annum, every practitioner commented upon the paucity of this support (L1LAP1/L1LAP3) with one noting,

*'it's not even 2 hours a week....unless you kind of use it every fortnight....But you know that's a break a fortnight it's not much is it'(L1LAP2).*

Secondly, eligibility criteria and policy absences actively exclude or neglect particular groups of risk-bearers from accessing statutory protection. These institutional gaps can leave certain care-givers' care-related risks either partially or fully privatised. Affected groups include: employed carers; part-time carers; carers providing fluctuating levels of care, short-term care, low level care, or domestic support; and older carers whose care-related poverty risks are not addressed. Where the poverty risks experienced by some of these groups are socialised it is on account of the state recognising the social risks of old age poverty or unemployment, rather than due to their informal care-giving status being recognised. The treatment of employed carers is also illustrative of the ineffectiveness of the carer strategies in practice. For each carer strategy considers work rather than cash benefits to be the preferred way to 'mitigate some of the negative financial effects of caring' (Department of Health, 1999, p. 88). Consequently, each strategy has assiduously promoted the reconciliation of work and caring roles as the key way to reduce the poverty risks that informal carers face

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<sup>159</sup> Low income carers are entitled to a benefit income of £103.60 per week (made up of Carer's Allowance and Income Support), JRF recommend single people have a weekly budget of £240.89 per week.



(Department of Health, 1999, p. 88, 2008, p. 85, 2010c). However, my data reveal that in practice there is a lack of integrated or adequate support across all three policy domains to facilitate carers achieving the objectives of either remaining in work, returning to work, or balancing their work and home life with caring. For their financial poverty risks are left privatised by the overarching system and their time poverty and associated welfare risks are only partially recognised and protected due to the inadequacy of the statutory employment policies and care support available.

This overarching research finding, that the English state does not treat informal care as a social risk in relation to any care relationship type, supports the argument made in Chapter 2 that all informal carers are made vulnerable to experiencing care-related risks because of the lack of value attributed to care by advanced capitalist states. The aforementioned inadequacy of state provision to address care-related risks ensures that these risks are privatised to some extent to all informal carers, regardless of their individual characteristics. However, the conceptualisation of social risk set out in Chapter 3 also highlighted the importance of recognising the increased vulnerability of certain groups of risk-bearers on account of their higher risk characteristics relating to social class, gender and age. Consequently, women and low income groups are the most negatively affected by the inadequacy of the state's treatment of informal care due to their characteristics increasing their likelihood of providing care and experiencing care-related risks. In the case of women, my research data reveal that state policies do not differentiate the level of statutory support provided to informal carers on account of their gender. However, the fact that women continue to undertake a higher proportion of care for both adults and children means that the implications of the state not treating care as a social risk are gendered, resulting in women experiencing greater poverty and welfare-related life-course risks than men. Census data show that women continue to spend longer durations of their life providing informal care than men (Office for National Statistics, 2014c). For example, in England males at age 15 can expect to spend on average 7.1 years of their remaining life providing unpaid care, compared with 9.3 years for females (Office for National Statistics, 2014c), meanwhile the proportion of life providing unpaid care at age 50 was 17.1 per cent for women and 15.7 per cent for men (Office for National Statistics, 2014b). Further data also reveal the prevalence of women, providing informal care between the ages of 24 and 64, and continuing to undertake the bulk of child care responsibilities during prime working age (Office for National Statistics, 2013b). The outcome of this gender imbalance in the provision of care is that women continue to be more likely to leave the labour market, or work part-time, in order to provide informal care than men (King and Pickard, 2013) and mothers' employment rates remain significantly lower than fathers'

(Office for National Statistics, 2012b).<sup>160</sup> Consequently, as noted in Chapter 3, women remain far more likely to experience immediate and extended financial poverty risks during working age and old age on account of their disrupted employment patterns (Evandrou and Glaser, 2003; Yeandle et al., 2006; Pickard, 2007; Yeandle and Buckner, 2007). Moreover, the greater incidence of women attempting to reconcile their work and caring roles or undertaking multiple caring roles for frail parents, children, and/or grandchildren simultaneously (Brown, et al., 2014; Office for National Statistics, 2013d), also ensures that during middle-age women are at greater risk of experiencing welfare-related risks than men (Dahlberg et al., 2007 in Office for National Statistics, 2013d). The inadequacy of the state's policy response across the cash benefits, care services and employment domains, for managing the immediate and extended life-course risks associated with informal caregiving, as revealed by my research findings, therefore continues to significantly disadvantage women more than men. Moreover, women's vulnerability to experiencing life-course risks in relation to childcare has been further compounded by the regressive actions of the Coalition Government to reduce Tax Credits, Child Benefit and contributions towards childcare costs, which has impacted on mothers' employment decisions and the incomes of lone parent households (Churchill, 2012). Wakabayashi and Donato (2006) warn that although privatising the life-course risks faced by informal carers and parents may save the state money in the short-term, it will make affected women more vulnerable to experiencing poverty and more reliant on the state in their own old age. The higher risk characteristic of social class also requires further mention. In Chapter 3 the case was made that an individual's risk of becoming a carer and managing the associated care-related poverty and welfare risks can be significantly affected by their socio-economic status (Anttonen and Zechner, 2011), with ELSA data showing a substantial burden of care to fall disproportionately on those in poor health and living in more deprived areas (Breeze and Stafford, 2010). More recent data from the 2011 Census show the average lifespan spent engaged in an informal carer role to be longer in the traditional heavy industrial regions of Northern England and the Midlands than in the South and East of England (Office for National Statistics, 2014c). Moreover, the provision of 50 or more hours of informal care per week was shown to be highest in areas of Merseyside, the North East and Midlands which are among the most deprived areas in England (Office for National Statistics, 2014c). Again this demonstrates how the lack of sufficient state support to protect informal carers against the care-related risks they face disproportionately affects traditionally disadvantaged groups, who face greater vulnerability on account of having the highest probability of engaging in informal caregiving and often the least financial resources for coping with the costs that this activity entails.

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<sup>160</sup> Labour Force Survey data from 2011 revealed only 30 per cent of mothers with dependent children worked full-time and 37 per cent worked part-time compared to 82 per cent and 6 per cent of fathers respectively (Office for National Statistics, 2012b).

In order to rectify the current systemic deficiencies of inconsistency, inequality and inadequacy and ensure the English state treats informal care as a social risk, the policy recommendations set out in Figure 36 would need to be implemented.

**Figure 36: Policy recommendations to ensure informal care treated as a social risk**

- Align the eligibility criteria of all care policy mechanisms to ensure parity of access to statutory protection exists across all types of statutory entitlements.
- Set lower eligibility thresholds to widen access to statutory support and protection to all affected risk-bearers.
- Address institutional gaps in protection for particular types of informal carers and higher risk groups through the provision of statutory support mechanisms which recognise and address their specific care-related needs and risks.
- Ensure all statutory provision is adequately funded so that comprehensive support and protection is provided to all risk-bearers against all care-related risks.
- Improve inter-agency working and the provision of integrated support across agencies and policy domains to ensure support solutions adequately address the multiple risks faced by informal carers, through the use of pooled budgets if necessary.

### **9.2.3 The production of secondary risks by state systems, processes and actors**

The previous sub-section discussed how the English state is inadequately responding to the primary risks connected with informal care-giving. Another key finding of this research project is that the policy system itself, through the way in which policies are designed and operationalised, also produces secondary risks. As noted in Chapter 3, these risks can occur when the system either maintains the recognised risks of certain risk-bearers, or exacerbates their risks by creating new financial or welfare risks (Kananen et al., 2006). These secondary risks can in turn present a significant barrier to the caring dyad accessing statutory protection against their primary care-related risks.

Some of the secondary risks generated by the English care policy system are a feature of a wider trend of risk-shifting which is occurring across post-industrial welfare states. As noted in Chapter 3, states, particularly neo-liberal welfare regimes such as the UK, are seeking to residualise their role in

providing statutory protection against social risks more generally. This is being achieved by adopting strategies which maintain the privatisation of risks and individualisation of responsibility for risk-bearers (Hacker, 2004; Whelan and Maitre, 2008; Beland, 2010; Ebbinghaus, 2012); and direct individuals towards market or family based 'solutions' (Crouch and Keune, 2012). These trends are evident in the care services domain where members of the caring dyad may be assessed to be eligible to receive statutory support on account of their level of need, but are expected to contribute towards the cost of that support via non-negotiable charges and in some cases additional top up charges set by the local authority. These charges, particularly for low income care relationships, can present poverty risks especially if support is required on an ongoing basis. Local authorities are also generating welfare risks by increasingly siphoning out the management of care and support services to care-receivers or their informal carers. This can occur when local authorities recommend universal services; promote direct payments,<sup>161</sup> and direct 'self-funders' to arrange their own care package privately. The numbers of people affected by these risk-shifting trends are not inconsiderable. Existing data reveal nineteen per cent of all adults over 65 who purchase community based social care services in England (751,000) pay privately for all their care, with a further 21 per cent paying private top ups for local authority funded services (Institute of Public Care, 2010, in Glendinning, 2012, p. 293). Both statutory trends can generate dilemmas and conflicts for caring dyad members on account of intra-relational risk-shifting. As noted in Chapter 8, this can occur where policy mechanisms meet the needs of one member but generate financial costs, time costs or stress for the other person. Furthermore, the research findings have also shown statutory policies and agencies to be continuing to treat families as resources within assessment and resource allocation decision-making processes and constituting obligations on them to continue caring. This goes against the 'carer blind approach' advocated by the Royal Commission on Long Term Care for the Elderly (1999 in Pickard, 2001) and the carer strategy recommendations which advocate that statutory agencies should not make assumptions that informal carers are always available, willing or able to provide care (Department of Health, 1999, p. 32, 2010c, p. 11; 19). Austerity measures which have resulted in substantial local authority budget cuts (Buckner and Yeandle, 2011; Lymbery, 2012) were also revealed to be exacerbating this trend, forcing local authorities to cut costs by reducing the length and frequency of the services provided and the type of support provided. These budget cuts have also had negative implications for the level of local authority funding awarded to specialist third sector agencies to provide carers services. Figure 37 illustrates how this has led to service cuts, waiting lists, and uncertainty about the future amongst third sector providers. All these state

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<sup>161</sup> Which is the government's preferred type of care delivery (Department of Health, 2010d).

actions can maintain the primary care-related risks experienced by care relationships as well as producing additional secondary risks.

**Figure 37: Implications of local authority budget cuts for third sector carers services**

*'We used to offer therapies....and the carers could have an hour appointment for £5. Unfortunately when the cuts came in we just had to cut that.'* (L1TS2M)

*'There is unmet need....unfortunately our counselling service we have got a 6 month waiting list....we don't want to expand, we haven't got the funding for it.'* (L2TS1M2)

*'Personal budget wise there is a limit because of the budget restriction they [LA2] have given us, which they have reduced for the third time now.'* (L2TS1M1)

*In LA1 the sitting service had originally provided '100 hours [per annum] and then because they ran out of budget it 'came to the 70 and 35.'* (L1TS1M)

*'I think [LA1] is pretty good as far as services but my concern is that it will get tighter as budgets have to be slashed....I hope the [carer] services will continue because they are needed but whether they do or not is in the lap of the gods really.'* (L1TS1M)

Secondary risks are also generated for care relationships due to the construction and atmosphere of the overarching care policy environment undermining access to the statutory support that is available, thereby reflecting some of my own research experiences discussed previously in Chapter 5. Firstly, the fragmented, complex, and opaque nature of the policy terrain can exacerbate the time poverty risks and stress experienced by care-givers. For it takes significant amounts of time and energy for care-givers to find out what statutory support is available and negotiate access to it. These are both resources that informal carers are in short supply of, particularly if their caring responsibilities continue unabated in the meantime. Secondly, some policy regulations intentionally extend care-related risks by incorporating time restrictions into their eligibility criteria. For example, applications for AA and by default CA, require the care-receiver to have had care needs for at least six months before any claim will be agreed,<sup>162</sup> and flexible working can only be requested once an employee has been in post for six months. Furthermore local authority resource allocation processes can significantly delay the caring dyad receiving support services. Given that '9 times out of 10....[carers] are at crisis point' (L2TS1M1) when they seek help from statutory agencies, these manufactured time delays can add significantly and unnecessarily to their stress. Thirdly, the lack of automatic entitlement to any disability or care-related statutory provision can produce additional

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<sup>162</sup> Unless they are terminally ill.

stress for carers in a number of ways. Uncertainty and anxiety can be generated because the caring dyad has no guarantee that any of their claims will be successful. Added to which the opacity of regulations and prevalence of discretionary decision-making obscures their ability to judge whether it is worth making the effort to try to access a particular type of support in the first place. Furthermore, state application and assessment processes place the onus on the care-giver providing appropriate evidence to *prove* their 'legitimate' caring status. Consequently, informal carers were noted to actively seek a formal endorsement from third sector carer organisations in an attempt to satisfy these demands and gain access to statutory support,

*'People come and say I want to register as a carer so I can prove I'm a carer' (L1TS2M).*

Moreover, in the cash benefit and care services domains, carers' evidence by itself is not considered sufficient proof, with their claims having to be counter-checked via the care-receiver's statutory entitlements. Overall this demonstrates an overarching lack of trust in informal carers' claims about their caring status which enhances the adversarial atmosphere of the policy environment. Added to which the chains of negotiations entailed within institutional processes are underpinned by unequal power relations between the caring dyad and state representatives. This contributes to the need for informal carers to fight for their rights to statutory support and protection from a vulnerable position. The policy environment itself, therefore, produces welfare risks by requiring informal carers to invest significant levels of physical and emotional labour in attempting to access statutory support. Moreover, these efforts may need to be sustained long-term, because providing care is a dynamic process and subject to change over time. Consequently, care-givers may find themselves facing these secondary risks at the beginning of their quest to gain access to statutory support and at subsequent intervals thereafter in order to address the care relationship's additional or changing needs. Some informal carers, particularly those with mental health or physical health issues or providing intensive levels of care, may lack the resilience, energy or time required to make this necessary effort, thereby ensuring their primary risk remain privatised and unprotected by the state.

One final way in which the primary risks experienced by care relationships can go unprotected is on account of the inadequacy of statutory systems for identifying informal carers. For example, one local authority representative noted,

*'....we know we have got around 20,000 carers... that is realistically how many we should have according to the census, we've got something like 2,000 which are known to our carer services....so....we really need to start identifying carers much earlier on' (L2LAM2).*

The need to make significant improvements in this area was noted to be a key priority in the latest carer strategy (Department of Health, 2010c). Health services have been identified as a key

problem<sup>163</sup> and a key solution for identifying informal carers and providing them with initial information about the types of support that are available, due to often being the first place carers go for help (Department of Health, 2008, 2010c). Third sector organisations are also considered critical to this endeavour (Department of Health, 2010c). However, one third sector representative raised concerns that the existence of carer organisations is being undermined by a lack of long-term financial security on account of local authority commissioning practices and budget cuts. A direct consequence of this was that within the next year their particular organisation expected to lose its 'shop front premises in the city centre' which was considered to be a key way of informal carers finding out about their service (L1TS2M).

In order to rectify the deficiencies within the care policy system which produce secondary risks and undermine primary risks being addressed, the policy recommendations set out in Figure 38 would need to be undertaken by the state.

**Figure 38: Policy recommendations to ensure secondary and primary risks are addressed**

- Redesign the care policy system to make it carer-friendly and promote carer awareness. This could be achieved by creating one central gateway through which informal carers can access:<sup>1</sup>
  - All information about the statutory support that is available;
  - A single assessment process through which carers can gain access to cash benefits and care services support;
  - Support from a specialist key worker who can help individuals to negotiate access to statutory support across the whole care policy environment.
- Ensure that existing statutory provision is adequately funded and responsive:
  - Remove all time restrictions from the policy regulations so that informal carers are able to access support from the start of their caring responsibilities;
  - Eradicate time delays in statutory support being provided.
- Promote trust within the care policy system:<sup>2</sup>
  - Remove the requirements from the policy regulations for informal carers to provide proof via themselves or the care-receiver that they are carers.

<sup>163</sup> '[Y]ou'd go into a [GP] surgery with 5,000 patients and they would have 23 [registered] carers. And you think that's not right, because 10% of the population are carers. So they are obviously not identifying them' (L1TS2M); 'some of the [GP] registers have 3 carers in them' [L2TS1M2].

- Eradicate policy designs which shift risks across members of the caring dyad.
- Raise awareness of, and promote the identification of, informal carers by practitioners and agencies:
  - All statutory agencies, including health agencies, to receive compulsory carer awareness training;
  - Provide ongoing guidance to staff about care-related entitlements and support services;<sup>3</sup>
  - Maintain adequate, long-term statutory funding of specialist carer organisations.

*Note:*

<sup>1</sup> The need for services to be accessible from one point within the system has previously been suggested by Barnes and Wistow (1993, in Barnes, 1997, p. 110).

<sup>2</sup> See Figure 41 for additional recommendations about how trust can be promoted.

<sup>3</sup> For example, in the JCP domain a national Carers Portal information database already exists which all JCP practitioners can access (L2JCM1).

### **9.3 Reflections on the nature of statutory entitlements in the care policy environment**

The findings obtained from this research have led me to question the extent to which the statutory outputs that are available to the caring dyad in England can be considered statutory ‘entitlements’, in the sense that similar beneficiaries are guaranteed access to uniform levels and types of protection. For it is clear that statutory ‘entitlements’ are far from fixed, particularly in the employment and care services domains, due to the influences of localism, practitioner discretion and personalisation. Consequently, the same care relationship could experience different statutory outputs on account of living or working in different places; being assessed by different workers; and due to an individual’s specific circumstances and wishes also potentially contributing to differential outputs. All of these potential sources of variation prevent the notion of uniform statutory entitlements for informal carers and care-receivers from being realised in the English care policy context. The extent to which this is problematic for care relationships and the treatment of informal care as a social risk requires consideration.

#### **9.3.1 Impacts of localism**

In the care services and employment domains, localism has contributed to the creation of a diverse system which ensures that individuals are subject to neither universal nor uniform levels of statutory



protection against the care-related risks they face. Local authorities, local JCP offices and districts, and employer organisations are permitted discretion as to how to discharge their statutory responsibilities through constructing their own policies and processes. This generates variations in the types and levels of statutory support outputs care-givers and care-receivers receive according to where they live, and in the case of carers, work. These locational differences in statutory protection are problematic because they produce territorial inequalities within a national state context which run counter to social justice principles (Powell and Boyne, 2001, p. 184; Kay, 2005) and undermine informal care being treated as a social risk by the state. For the care-related poverty and welfare risks experienced by the caring dyad may be protected in one locality or organisation but maintained or exacerbated in another, due to variations in the statutory support provided and the secondary risks generated by policies and processes such as financial charges etc. These variations call into question whether the term 'entitlement' can be applied to the inconsistent statutory support available to the caring dyad in these domains. Even so, government and national third sector interviewees did not consider the variation in the level of resources that different local authorities commit to supporting informal carers and the diversity of the services they provide to be problematic (NGPR/NTSPR). Instead both argued in favour of local government, rather than national government, continuing to assess and determine local needs and commission different services to meet those needs. However, the fact that informal carers ultimately tend to have broadly similar universal needs calls into question the extent to which decisions about the types of services that local authorities and statutory agencies provide need to be locally determined. For as one third sector representative noted,

*'what carers tell us they want is....information and advice about what they are entitled to....and the sort of the support they can get for the person they care for....and they want practical support, which is replacement care, so they can have a break from their caring responsibilities. And those are really the three main strands that carers want....and every local authority in the country will do carers questionnaires and they will go out to carers and ask them what services they want....and at the end of the day it keeps coming back, all the research is there that says this is what carers want' (L1TS1M).*

Another concern that localism generates relates to the weakness of the 'levers' for holding statutory agencies to account and ensuring that informal carers' interests are protected. Some local authorities are known to provide inadequate support for informal carers or to have misinterpreted existing policy guidance (NTSPR/NGPR). However, it is considered the responsibility of individuals and organisations within the locality to scrutinise local authority policies and practices and hold local

authorities to account (NGPR). The ability of local carer organisations to undertake this role was acknowledged to be hampered by a lack of information,

*‘There is very little transparency at local level.....And, you cannot have a system based on local accountability where you can’t get hold of any information. How can you hold someone accountable if you can’t find out what they are doing’(NTSPR).*

Moreover as previously noted, individual carers are unlikely to have the time and energy required to challenge local authorities, particularly as they are the ones directly affected by the lack of adequate support being provided in the first place. Furthermore the ability of informal carers and carers’ organisations to challenge the inadequacy of the statutory support provided in any domain is undermined by unequal power relations, which in the case of carer organisations emanates from their financial dependency on statutory funding.

To eradicate the inconsistency of statutory support generated by localism, the policy recommendations identified in Figure 39 would need to be implemented by the state.

**Figure 39: Policy recommendations to address territorial inequalities in statutory outputs**

- Territorial inequalities in the level and type of statutory support available to be actively discouraged by the implementation of more prescribed national legislation and policy guidance. This would have the following benefits:
  - The standardisation of support services and employment policies would increase the transparency of the policy environment through ensuring more universal and uniform entitlements are available. This in turn would promote carer and practitioner awareness of those entitlements.
  - The treatment of informal care as a social risk would be promoted by guarding against individuals being unfairly subjected to different levels of statutory protection solely on account of their location.
  - Clearer national guidance and standards about expected statutory outputs would facilitate agencies and organisations being challenged if deemed to be failing in their statutory duties to provide the necessary support to care relationships.
- Central government to assume responsibility for regulating the care policy environment to ensure that all statutory agencies and employers are upholding their statutory responsibilities and providing lawful and adequate support.

### **9.3.2 Impacts of practitioners**

The inconsistent levels of statutory protection that different care relationships can experience on account of practitioner-based variations are also problematic but more difficult to counteract. The research data confirm previous research findings that variations in the statutory support provided to policy recipients can occur due to street level bureaucrats applying their own interpretations to the statutory regulations (Lipsky, 1980). However, the data reveal how individual practitioner's personal attributes, experiences, and the extent to which they are prepared to invest their own emotional resources and energy into advocating on behalf of the caring dyad within complex and often adversarial internal negotiation processes could also significantly affect their decision-making about the caring dyad's statutory support outputs. For practitioners in the care services domain in particular, did not discuss the care policy environment in neutral terms but described it to be difficult, fraught and frustrating. The interactions between practitioners and managers were mainly described as antagonistic and conflictual (Lipsky, 1980) rather than cooperative and supportive (Evans, 2010, 2011; Ellis, 2011). Moreover in keeping with previous studies' findings, managers (Ellis, 2011; Evans, 2010, 2011) and practitioners (Carey and Foster, 2011) were found to use a range of conflicting strategies within their negotiations to gate-keep, and advocate for, statutory resources respectively. Budget cuts emanating from austerity measures were also revealed to be increasing the adversarial nature of both internal and external negotiations, thereby potentially increasing differential statutory outputs being provided across care relationships and across time. It is also possible to discern that even the decisions made by each individual practitioner may vary over time, or fluctuate according to the specific care relationship they are working with, or on account of the type of support services that are required.

To rectify the inconsistency of statutory support generated by practitioners, Figure 40 identifies some key policy actions that would need to be taken by the state. However, none of these recommendations can resolve practitioner generated inconsistency in statutory outputs entirely.

**Figure 40: Policy recommendation to address practitioner-based inequalities in statutory outputs**

- The provision of compulsory and regular practitioner training sessions about:
  - the legislation, policies and regulations affecting the caring dyad;
  - the service provision available nationally and locally.

This would help to reduce variations in service outputs on account of practitioner ignorance or misinterpretation.
- Greater standardisation of eligibility criteria and more adequately resourced adult social care provision would potentially help to promote equity across assessment outcomes and statutory support outputs.

### **9.3.3 Impacts of personalisation**

The inconsistency in statutory outputs caused by personalisation can be less easily condemned as problematic in the first instance. Ellis (2007, p. 411) previously found social workers to be concerned about individuals using their Direct Payments to purchase items such as electric scooters and health club memberships because they considered these choices to offend the bureaucratic principle of equity. On the one hand this concern can be deemed to be reasonable and justified. It relates to my own concern about variations in statutory outputs undermining the principle of providing universal and consistent entitlements, and contributing to the opacity of the policy domain. However, the state's wish to provide statutory support in the form of a personalised response to meet the specific needs of each care relationship is not unreasonable. For in many ways this type of statutory response demonstrates a responsiveness to individual circumstances, and a level of trust in individuals selecting the types of support that will best suit their needs, which is missing from other elements of the policy environment. Barnes (2012, p. 181) even considers that the way in which personalisation emphasises the need for attentiveness to individual need has the potential to reflect an ethics of care. Moreover, a more personalised approach is also apt for managing the unpredictable and diverse nature of elder care, which Phillips et al. (2002) consider to require more customised, tailor-made solutions and policy responses.

However, the research findings reveal that these potential advantages of personalisation have been undermined by the way in which this policy has been implemented and operationalised. Firstly, the caring dyad's ability to determine how their specific needs are met is restricted by the legislation which stipulates who can be employed as the carer; local authority policies which determine how

direct payments can be used; and the inadequacy of the statutory funding provided, which is being worsened by 'austerity measures'. In terms of the latter one manager noted,

*'The...thing I am concerned about in this current climate is.....that we will lose personalisation, because we've got to this financial point where people are really crunched, some of that creativity and actually looking for solutions which are going to suit the person more.....sometimes that's lost' (L1LAM1).*

Moreover, practitioners and managers were found to make assumptions about the support that would best meet the caring dyad's needs: by withholding information thereby preventing the caring dyad from making informed decisions; and refusing funding requests based on the caring dyad's wishes. All of these factors highlight a continuing lack of trust shown towards care relationships. Secondly, personalisation is being operationalised in a way which generates secondary risks for care relationships. It is transferring care management and welfare responsibilities from the state onto the caring dyad, including the responsibility for managing the quality of care provided to care-receivers (Ferguson, 2007; Needham, 2011; Barnes, 2012). Moreover, inadequately funded personal budgets can generate financial risks and potential care deficits for both members (Lloyd, 2010; Barnes, 2012, p. 181). Both factors have the potential to cause intra-relational conflicts between care-receivers and care-givers within the private sphere. Thirdly, personalisation, even if adequately funded, can as noted by Barnes (2011) present a significant social justice issue. Because unless sufficient guidance and support is made available to potential recipients, those groups who are already more vulnerable to experiencing inequality on account of their age, educational status, and health status may find themselves marginalised from accessing this type of support and the benefits it can bring. As noted in Chapter 4, individuals have differing abilities and capacities for managing the key elements of personalisation (Glendinning, 1998a; Clarke, 2006; Ellis, 2007; Lymbery, 2010; Moffatt et al., 2012). The key components of self-assessment and personal budgets require: self-awareness of, and the ability to articulate, needs and wishes; and knowledge, confidence and competence to use this type of care delivery. Moreover, practitioners, particularly in LA1, noted actively excluding older people from accessing direct payments due to concerns and assumptions that they would struggle to cope with this type of support. The state, therefore, needs to recognise and provide suitable support and protection to enable more vulnerable groups to benefit from the freedom and choice that personalisation can offer.

If sufficient financial and human resources are provided, personalisation should, according to Barnes (2012), enable each care relationship to access statutory responses that will meet the particularity of their own needs. Consequently this would enable social justice to be achieved across care

relationships in diverse circumstances (Barnes, 2012). This viewpoint offers a resolution to the tension wrought by my previous assertion that in order for informal care to be treated as a social risk by the state it requires consistent statutory support outputs to be provided across similar care relationships. Because although personalisation creates diverse statutory responses, the universal protection of risk-bearers could potentially be achieved if each care relationship is provided with adequate overarching statutory support to meet their individual needs according to their specific wishes. In this way the care policy system could provide both universal protection and real choice to informal carers and care-receivers about how their needs can best be met which is missing from the current system.

To rectify the current deficiencies of personalisation, Figure 41 identifies the key policy recommendations which would need to be implemented by the state.

**Figure 41: Policy recommendation to address personalisation-based inequalities in statutory outputs**

- More adequate training to be provided to practitioners to promote their understanding of personalisation and how these approaches can benefit individuals if implemented appropriately.
- Statutory agencies to:
  - provide the caring dyad with the necessary information to make informed decisions;
  - trust risk-bearers to make their own decisions about the type of support that they consider will best meet their needs.
- More adequate levels of statutory funding are required to ensure that personalised support is conducive for meeting the needs of care-receivers and care-givers and does not generate secondary risks.
- More administrative support, human resources and training are required to enable all risk-bearers to benefit from personalised care and support irrespective of their needs and abilities.

## 9.4 Reflections on the treatment of informal carers by the state

### 9.4.1 The unique position and treatment of informal carers in the English welfare system

Informal carers occupy a unique position in the English welfare state due to the nature of their contingency which in turn has affected their treatment by the state. All other risk-bearers who receive statutory protection do so on account of experiencing a specific contingency themselves which directly impacts on their welfare or ability to access the labour market as in the case of old age, disability or unemployment. In contrast informal carers require support on account of providing care to another person who is the individual directly affected by illness or disability. The 'indirect' nature of the contingency which informal carers experience, together with the lack of value and recognition attributed to the activity of care by capitalist states, discussed previously in Chapters 2 and 3, has ensured their differential treatment by the welfare state. Consequently, informal carers were one of the last groups of risk-bearers<sup>164</sup> to be recognised by the English state, long after the initial welfare reforms of the liberal government (1908-11) and post-war welfare state had been implemented. The first formal recognition they received was the implementation of the Carers Allowance in 1976, followed approximately 20 year later by acquiring a right to carers assessments in the care services domain (HM Government, 1995).

In addition to being unique due to receiving belated statutory recognition of their risk-bearer status, informal carers are also subject to unique treatment by the state. This is evidenced by their marginalised positioning within the welfare system and predominant treatment as a resource by the state. In terms of the former, the findings in Chapter 7 reveal how informal carers and their statutory entitlements are not embedded in the welfare system to the same extent as other risk-bearers. This is due to the contingent nature and weakness of their rights to statutory support and protection; and their peripheral positioning in each policy domain. This is reflected in the way in which they are often treated as a secondary consideration within institutional processes, as illustrated by one local authority manager who noted,

*'I think the social care agenda is so massive carers tend to be seen as, because they're not the person who is being looked after, I think people tend to see them in second place. So we've got lots of stuff going on for older people....if you have got an illness or....condition yourself there is an agenda for you and there's money attached to that [whereas] people tend to see [supporting carers] as something nice to do rather than an essential' (L2LAM2).*

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<sup>164</sup> Fathers are the other group of latecomers, having only been granted rights to paternity leave in 2003 to manage their care-related welfare risks.

Moreover, the statutory support that informal carers can access is often designed to meet the needs of other risk-bearers, rather than recognising or addressing carers' specific needs. In terms of the latter, I return to Twigg's care-giver model typology (Twigg, 1989) to summarise the overarching treatment of care-givers by the English state. The state's intention across all three policy domains initially appears to be to treat recognised care-givers as 'co-workers'. A range of statutory support in the form of cash benefits, carer services, replacement care services for the care-receiver, and employment rights are provided by the state. The carer strategies note that much of this support is intended to serve the instrumental purpose of ensuring the continuation of the care-giving role for different types of care-givers (Department of Health, 2008, p. 108). However, the inadequacy of the state provision that is available for recognised care-givers and the lack of support provided to unrecognised care-givers, ensures that informal carers are primarily treated as resources by the state. For policy absences clearly place full responsibility on families to continue caring, meanwhile the provision of minimal levels of statutory support to recognised care-givers only serves to ensure that the family as the key care provider is not completely overwhelmed.

#### **9.4.2 Policy process factors affecting the state's treatment of informal carers**

In order to understand the English state's inconsistent recognition and treatment of different types of risk-bearers, it is necessary to explore the multiple strands of policy complexity underpinning the policy process. This includes analysing the piecemeal way in which the statutory entitlements of informal carers have been awarded by the state, and how inconsistent policy trends have affected the development of care policies in England due to the state engaging in a process of policy expansion and retrenchment concurrently on account of demographic, economic and fiscal pressures (Beland, 2010; Häusermann, 2012). This analysis requires the factors, discussed previously in Chapter 3, which influence the process whereby a social risk becomes formally recognised by the state as requiring some form of statutory intervention, to be considered. This includes the extent to which the English state has recognised informal care as a social risk because it presents some kind of social threat or benefit which warrants public intervention and support, and the role that claims-making by carers' organisations within the political process has played in the development of statutory protection to address informal carers' care-related risks.

Initially the policy trend underpinning the development of care policies in England to support informal carers was one of expansion. Since 1976 different types of informal care-givers have gradually gained statutory entitlements to address particular needs and risks. The claims-making of carers' organisations was critical to these initial successes (Barnes, 2001). These organisations were



instrumental in promoting the state's recognition of informal care as a social risk and for mobilising informal carers as a political force to campaign for social rights and protection. However, the incremental gains in statutory protection that were made highlight the way in which carers' organisations have often represented the needs of particular types of care-givers who actively engage in these civil society groups. For example, the primary concern of the first national carers' organisation, the National Council for the Single Woman and Her Dependants (NCSWD), was the financial needs of single female carers caring for their elderly parents (Barnes, 2001). Their campaigning led to the state implementing Invalid Care Allowance (ICA) in 1976, which sought to address the poverty risks of single female carers and male carers only (Barnes, 2001; Arksey & Kemp, 2006; Carers UK, 2014b). By the 1980's the membership of carers' organisations had broadened (Rogers & Barnes, 2003; Stalker, 2003) and these groups proved instrumental to ICA being extended to married women in 1986 through sponsoring the test case of married carer Jackie Drake through the European Court of Justice (Walker & Walker, 1991). Despite these successes, the needs and views of certain groups of carers were still not adequately represented by these civil society groups, including young carers (Williams, 2012), black carers who set up their own support network in 1998 (Carers UK, 2014b), older carers, and gay, lesbian and bi-sexual carers. Moreover, carers' organisations' campaigns had focused on extending statutory protection to carers providing higher levels of care, rather than 'part-time' carers. Consequently, Carers Allowance and the Private Member's Bills secured by carers' organisations (Carers UK, 2014b) which led to the implementation of legislation in the care services domain (HM Government, 1995, 2000, 2004) only provided statutory provision for carers providing substantial amounts of care.

Arguably the specificity of carers' organisations' claims-making may also reflect their pragmatism in acting on behalf of those groups whose claims are more likely to be considered legitimate and 'deserving' by the state, thereby enhancing the likelihood of political intervention (Fraser, 1989). This point corresponds with Williams (2010; 2012) argument that successful claims-making depends on affected groups of risk-bearers identifying suitable opportunities to politically engage in institutional spaces, which includes tailoring their demands to the key policy discourses of the state. However even when states recognise particular risk-bearers' demands, they may re-interpret their claims and design the policy outputs in accordance with their own policy frames in order to serve alternative policy objectives (Williams, 2012). These political processes and effects are evident in the care policy domain. For example, Rogers and Barnes (2003) note that informal carers' claims for legal rights to social services support were granted during the period that community care policies, which are reliant on informal care to succeed, were being enacted by the state. Meanwhile,

parental demands for child care were deemed to be successful because states could harness these claims to their social investment policies which aimed to increase the labour market participation of under-represented groups, such as women, in order to promote economic competition and growth (Lewis, 2006; Williams, 2012). Williams (2012) similarly attributes the political recognition of the need to support employed carers in the 2008 carer strategy to carers' organisations tailoring carers' claims to New Labour's social inclusion and employability discourses, by highlighting the lost productivity of carers forced to exit the labour market and marketing informal carers as potential earners. Arguably this formal recognition was also linked to these claims aligning with the activation policies of successive governments, promoting work over welfare in order to reduce dependency on cash benefits and contain social expenditure (Arksey & Kemp, 2006; Williams, 2010; Cantillon & Van Lancker, 2013). However, Williams (2012) warns that restricting claims to appeal to political audiences can undermine social justice and equality principles, which can only be achieved when claims are based on equality of outcomes for all affected risk-bearers (Williams, 2010). This helps to explain why the 'successes' that have been achieved by carers' organisations' claims-making in England, whilst undoubtedly significant, appear at best as compromises rather than outright gains. For the specificity of their claims-making in representing the needs of particular types of carers and their willingness to attune their claims to accepted state discourses has arguably contributed to the resulting deficiencies in the statutory provisions for informal carers discussed throughout this thesis. This targeted claims-making approach has undermined informal care being recognised and treated as a universal social risk for all informal carers and permitted inadequate and inconsistent statutory protection to be provided to different types of informal care-givers to address their care-related risks.

A key area where the limitations of carers' organisations' claims-making is evident relates to carers' flexible working rights, a policy area where carers' statutory protection has recently been retrenched. This example illustrates how the claims made by carers' organisations have been harnessed by the state in order to fulfil its own policy objectives of promoting the flexibilisation of the workforce as part of the productivity agenda (Lewis, 2006 in Williams, 2010; Häusermann, 2012). It also highlights how claims-making groups who form alliances with more powerful actors such as employers (Timonen, 2004; Bonoli, 2005, p. 433), may find those actors co-opting or subverting their claims to suit their own economic interests (Taylor-Gooby, 2004a; Hutter, 2006). The reform of the Employment Rights Act 1996 in June 2014, extended the statutory right to request flexible working from parents and carers to *all* employees (Acas, 2014). This reform was strongly advocated by an employer organisation set up with a specific brief to support working carers, which is coordinated by

a national carers' organisation (Carers UK, 2014c). A representative of this organisation focused solely on the positive implications of this reform for carers, which extends this right to formerly excluded groups of carers and destigmatises and 'normalises' flexible working for all employees (ETSM1). However, they did not acknowledge the potential for this new universal right to undermine carers' access to flexible working, on account of increasing numbers of requests being made across employees, coupled with the inability of employers to discern or prioritise between the urgency or necessity of those requests because employees are not required to justify their reasons for wanting flexible working. Furthermore, no mention was made of the loss of employees' statutory rights to an appeal if employers reject their request (Gov.uk, 2014b). Moreover, the pre-existing deficiencies of the legislation for informal carers, discussed previously in Section 7.4.3, remain unchallenged and unchanged. These points illustrate how this carers' organisation has supported a reform which furthers the interests of larger, more powerful political constituencies at the expense of adequately protecting carers' specific needs.

Further examples exist of the state intentionally retrenching the statutory support provided to informal carers in other policy domains. However, despite this eroding specialist provision for carers, carers' organisations have been reluctant to counteract some of these actions when they are underpinned by particular policy discourses. For example, the state's decision to remove ring-fenced protection from the Carers Grant in the care services domain; and the loss of specialist carer roles amongst strategic managers and practitioners within JCP, have been influenced by central government's focus on advancing localism. Although several interviewees from local carers' organisations called for ring-fencing to be reinstated (L1TS1M/L1TS2M), one national carers' organisation representative stated that they would not challenge this government decision and constructed the issue as an unwinnable battle,

*'...there is no point in arguing for ring-fencing, it doesn't matter whether I think it's a good idea or bad idea....the whole point of localism....is to allow local decision making. If you ring-fence things you have already decided so that's not a local decision....so we don't even argue for ring fencing....you are just wasting your time. I'd rather argue for something that we'd actually win' (NTSPR).*

Meanwhile in the cash benefits domain, the ineffectiveness of carers' organisations lobbying on issues that do not align with the state's welfare and austerity discourses can be seen. National carers' organisations have persistently challenged the insufficiency of cash benefits provided to informal carers (Carers UK, 2015a). Even so, the Welfare Reform Act 2012 (HM Government, 2012b) has wrought changes to the disability benefits of working-aged people which, while not directly relevant to my thesis, are notable for highlighting how government reforms are eroding existing

statutory protection for informal carers more generally. A government impact assessment conducted in 2012 estimated that 28 per cent fewer disabled people will be entitled to the new Personal Independence Payment, meaning that between 5,000 to 10,000 carers could lose their entitlement to Carers Allowance (McIntosh, 2013). If, in due course, the disability benefits of people over 65 are similarly retrenched then the benefit entitlements of the informal carers of older people are also likely to be negatively affected. Moreover, a carers' organisation representative raised concerns that 'alot of carers will lose out' if Carer's Allowance is in time subsumed into means-tested Universal Credit (NTSPR).

Meanwhile, the English state is undertaking a simultaneous process of expanding and strengthening carers' rights in the care services domain. The Care Act 2014, which replaces the existing patchwork of social care legislation and policy guidance analysed in this thesis, looks set to address many of the existing institutional deficiencies identified within this policy domain. A key policy driver for implementing the Care Act 2014 (HM Government, 2014), 'the most significant reform of [adult] care and support in more than 60 years', was noted by Care and Support Minister, Norman Lamb, to be the institutional threats presented by population ageing (Lamb, 2014). However, carers' organisations and the independent government advisory body, the Standing Commission on Carers, have also influenced this legislative reform through claims-making and advocating on behalf of carers respectively (Carers UK, 2014d, 2015c). Together these factors have aligned to produce improved support for informal carers in a number of areas, although not all. Firstly, the strength of informal carers' rights are now equivalent to care-receivers' rights. Local authorities have a duty to assess adults and carers who have *any* level of needs for support and must provide support to meet any individual's eligible needs; with both carers and care-receivers being granted a statutory right to a personalised care and support plan and personal budget. Secondly, a carer's eligibility to access support no longer depends on the care-receiver's needs thereby reducing the derived nature of informal carers' rights to support, moreover the care-receiver's eligibility must be determined on a 'carer blind' basis (Department of Health, 2014). These provisions will potentially enable statutory protection to be extended to those care relationships requiring and providing lower levels, or fluctuating levels, of care (Department of Health, 2014, p. 89; 90). More affluent care relationships will also be able to access greater statutory protection due to a cap being applied to personal care expenditure thereby providing regressive protection against unlimited financial costs being accrued (Department of Health, 2014, p. 111). However, the extent to which the Act will address the secondary risks produced by institutional systems and regulations is more mixed. The following changes have the potential to address some of the social justice concerns raised previously and

promote equality of outcomes. The regulations stipulate that personal budgets must always be sufficient to meet any individual's care and support needs. Meanwhile local authorities will have an active duty to promote informed decision-making: by providing accessible information and advice about personalised care and support planning, managing a direct payment and local support services; and by using independent advocates to support more vulnerable individuals (Department of Health, 2014, p. 137). Furthermore, the duty on local authorities to establish and maintain an information and advice service together with the consolidation of multiple stands of legislation into one statute will potentially promote greater awareness about the entitlements and support that are available. However, financial inequalities and potential intra-dyadic conflict will persist on account of top ups still being permitted; and all replacement care services to support carers being categorised as care-receivers services which leaves them liable to pay financial charges (Department of Health, 2014, p. 158; 164). Furthermore, territorial variations will remain, despite a new national minimum eligibility threshold and a single legal framework for financial charging being implemented. This is because local authorities will be able to continue to apply more generous eligibility thresholds and determine whether or not to charge individuals for the support they receive (Department of Health, 2014, p. 109). Overall then, this reform provides a legislative framework with the potential to improve the consistency, adequacy and sensitivity of the support provided to the caring dyad in the care services domain. However, whether this can be achieved in reality is dependent upon local authorities being provided with sufficient funding to implement this reform (Clements, 2014; Carers UK, 2015b). Moreover, these reforms will do nothing to eradicate the inconsistent and marginalised treatment experienced by informal carers across the overarching care policy environment. By itself, this reform, therefore, does not constitute the fundamental reform that is required to ensure informal care is treated as a social risk, it remains only a step in the right direction.

This discussion has considered the factors within the policy process which have prevented the state from treating informal care as a universal social risk for all risk-bearers and resulted in a lack of adequate, comprehensive and consistent statutory protection being provided to informal carers by the state. Some elements of the state's marginalisation of informal carers, such as the retrenchment of support, appear purposeful, because it is linked to the intentional design of state processes, policies and discourses. Meanwhile other systems effects, such as the inconsistent treatment of care relationships and care-related risks across policy mechanisms on account of the non-alignment of eligibility criteria and characteristics, appear inadvertent, a result of happenstance and oversight on the part of policy-makers. These oversights may be attributable to the piecemeal development of carers' rights and entitlements over time and the fragmented nature and complexity of the care

policy terrain. This has arguably resulted in gaps in statutory protection and unintentional inconsistencies in statutory outputs occurring, which are subsequently left unaddressed. In Chapter 3, it was noted that the ability of carers as a political constituency to challenge these policy shortfalls is undermined by the size and heterogeneity of their individual needs and characteristics (Lloyd, 2006a), and the time and energy constraints of the caring role itself. This can limit their engagement in carers' organisations which are the key forum for voicing carers' needs and claims in the political arena. However, the claims-making of carers' organisations have also contributed to these outcomes. Social investment discourses and activation policies promote the activity of work over that of care. Consequently constructing claims, supporting policies, and being co-opted by the main beneficiaries of these work-centric discourses, can leave the care-related risks of a diverse range of informal carers unaddressed and undermine social justice for all risk-bearers from being achieved (Cantillon and Van Lancker, 2013).

## **9.5 Reflections on the extent to which care is valued by the English state**

In this final section I consider what my findings reveal overall about the extent to which care is valued by the English state.

### **9.5.1 Assessing the English care policy environment according to the principles of an ethics of care**

In Chapter 2 the feminist literature stipulated a number of principles relating to an ethics of care which can be used to assess the extent to which care is supported and genuinely valued in a society. The care policies and practices in England can be assessed according to their attentiveness to noticing the needs of others; their assumption of responsibility for meeting those needs; whether they promote competence in care-giving; and their responsiveness to the vulnerabilities of those engaged in the activity of care (Tronto, 1993, pp. 106–108). These principles are linked to the state's recognition of the diversity and inter-relatedness of care; the adequacy of the statutory support provided; and the extent to which individuals are granted choices in relation to care. By assessing the findings of this care policy analysis against these criteria it reveals that the English state does not treat informal care in accordance with an ethics of care.

### **9.5.1.1 Attentiveness and recognising diversity**

Part of the assessment to discern whether an ethics of care exists requires consideration of how state institutions make judgements about recognising and establishing needs and negotiating how those needs can best be met (Williams, 2001; Barnes, 2012). According to Barnes (2012, p. 20), a failure to recognise or name a particular experience where needs do actually exist amounts to inattentiveness to the need for care or suffering experienced by specific individuals or particular groups. For an ethics of care to be realised, state policies therefore need to recognise the diversity of care and care relationships, and acknowledge that caring is not one uniform experience but is multi-faceted (Watson and Mears, 1999, p. 176). Barnes' (2012) previously noted that some areas of the English care policy environment do allow for greater attentiveness than others. For example, access to care services is based upon the context of particular circumstances, which allows practitioners to be attentive to whether a need exists and how it should be met (Barnes, 2012). However, the cash benefits system does not allow for such attentiveness due to eligibility being based on fixed criteria, which as one Government commissioned Income Task Force acknowledged does not reflect that informal carers are a disparate group (Calderwood and Harker, 2008). Moreover, although the national carer strategies (Department of Health, 1999, 2008, 2010c) explicitly acknowledge the diverse nature of care, caring and informal carers' needs, my research findings clearly reveal that existing policy mechanisms and practitioners do not allow for the whole range of care-related needs and care experiences to be recognised. The inconsistency found across the eligibility criteria of policy mechanisms and the statutory support outputs of care relationship types, exposes how some group's needs receive statutory attention while the needs of others are ignored. Consequently my findings support the conclusion that the English care policy terrain is not attentive to the care-related needs and risks of all informal carers or care-receivers.

### **9.5.1.2 Responsibility, adequacy and competency of support**

In order to determine whether an ethics of care exists states also need to be assessed in relation to whether they accept responsibility for ensuring care for their citizens (Barnes, 2012, p. 22). This requires care policies and the adequacy of state funding to be analysed in relation to what they illustrate about the state's assumptions about where responsibilities for care-giving lies; and the level of responsibility the state conceives itself to have to ensure the needs of those engaged in care are met (Barnes, 2012, p. 149). The research findings clearly show that the English state does not take adequate responsibility for meeting the needs of individuals engaged in caring nor for the activity of caring itself. Consequently, the risks associated with care are neither comprehensively nor adequately socialised. This is demonstrated in the way that gaps in statutory protection exist;

inadequate levels of support are provided; and individual and family responsibilities for managing care needs and risks are maintained even where the need for support has been recognised. Lloyd (2006b) notes that the shifting of responsibility for managing needs onto individuals entails avoidance rather than acceptance of state responsibility. Moreover, Barnes (2012, p. 83) states that limited public resources cannot be claimed by states as a reason for not taking responsibility to meet care-related needs. However, 'austerity measures' implemented in response to the financial crisis have been explicitly used by the English state to justify extensive local authority budget cuts<sup>165</sup> which have resulted in the increased rationing of statutory support. The inadequacy of statutory support on offer also undermines another element of the ethics of care from being realised, which is the ability of individuals to provide competent care. Failure to provide appropriately resourced statutory support to care relationships can result in poor care practices if care-givers are unable to meet their own needs or the needs of other people who depend on them adequately. This can ultimately expose individuals within care relationships to the risk of abuse, neglect and exploitation.

### **9.5.1.3 Responsiveness, the inter-relatedness of care, and choice**

To achieve an ethics of care in practice, the state must also be responsive to the needs of those engaged in care. This requires care policies to be designed which are able to recognise the inter-related nature of care, and grant care-givers *and* care-receivers real choices in relation to care with statutory support and rights being provided which empower both members (Barnes, 1997, p. 118, 2012; Williams, 2004). In relation to the former, states can find it difficult to strike the balance between recognising and protecting the rights of individuals to their own statutory support and protection while at the same time ensuring that the inter-related needs of the caring dyad are recognised in a way which provides the most effective support to meet the care relationship's overarching needs. Although the English state has explicitly acknowledged the importance of recognising the inter-relational nature of care in the carer strategies,<sup>166</sup> the research findings reveal how actual care policies and institutional practises struggle to manage this inter-relational dimension in a number of ways. Firstly, in Chapter 7, the state was revealed to have predominantly focused on providing care-givers and care-receivers with individual rights to support. In the care services domain this had led to the institutional disaggregation of the caring dyad within separate assessment and resource allocation decision-making processes. This was found to have actively

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<sup>165</sup> For example, it was noted that LA1 had got to make £40 million pounds worth of savings in 2013-2014 (L1TS1M), meanwhile the LA2 website (2012) noted adult social care to be required to reduce expenditure by 30 per cent (£17.5 million) over 4 years.

<sup>166</sup> 'Carers and their caring role are inextricably linked to the people they care for. If the support and services are not right for the person being supported then both the individual and family are affected' (Department of Health, 2008, pp. 16–17).



undermined statutory support outputs responding to the needs and wellbeing of the care relationship as a whole. Secondly, where informal carers' cash benefit and care support entitlements appear to take the inter-related nature of the caring dyad's needs into account, they do so in a way which weakens carers' own rights to support by making their rights contingent upon the care-receivers' needs. This treatment shows a lack of trust in the informal carers own claim for statutory support and can ultimately undermine the care relationship from gaining access to adequate levels of support. Thirdly, the construction of state policies can also fail to acknowledge the inter-relatedness of care by either recognising only one party's needs or risks, or reinforcing inequalities between the members of the caring dyad (Barnes, 1997; Williams, 2004, p. 10). This treatment is found in the ways in which state policies shift risks across caring dyad members, and where the disaggregation of institutional decision-making processes allow care-receivers' needs to take precedence over care-givers' needs. Both institutional responses set members of the caring dyad in conflict with one another rather than recognising and addressing both sets of needs and risks simultaneously.

The state's responsiveness to the inter-relational nature of the caring dyad's needs could also be demonstrated through the provision of flexible policies which people can adapt to suit the individual needs of their care relationship (Williams, 2004, p. 10); and care relationship members being provided with real choices about the way in which their needs are met. Policies need to ensure informal carers have the right to choose whether or not to care and how to provide care, and care-receivers have the right to choose the level and type of care they receive and from whom (Williams, 2001; Rummery and Fine, 2012; Barnes, 2012). However the research findings reveal how the statutory support that is currently available in the English care policy system is neither adequate nor comprehensive enough to provide care relationships with real choices about care. Consequently, care-givers are currently not able to provide care, should they wish to do so, without significant disadvantage to themselves (Kittay, 2001; Barnes, 2012). Moreover, although the potential exists for states to be attentive and responsive to the diversity of individual care relationship's needs through the application of personalisation, as already noted in section 9.3.3, the findings reveal how multiple restrictions in the form of regulations, professionals, and inadequate resources, prevent this from being achieved. The care policy environment therefore continues to lack the necessary flexibility, choice and trust in those affected by care to enable the state to be fully responsive to the needs of each care relationship and promote their overarching wellbeing.

### **9.5.2 Final reflections on the value attributed to care by the English state**

By comparing the research findings to what feminist scholars argue the principles of an ethics of care should look like in practice, it is possible to discern that care is not valued by the English state. When considering the attentiveness, responsibility, competence and responsiveness of the overarching care policy system to the needs of members of the caring dyad, it is clear that the system lacks the adequacy and integrity required to achieve an ethics of care in practice. The way in which care-givers are treated inconsistently and primarily as resources; leaving their care-related risks only partially protected or unprotected; and the lack of trust shown in them by statutory support systems, confirms that informal care-givers are not treated according to an ethics of care and are not valued by the state. Consequently, despite the implementation of an array of care policies, the English care policy system continues to place a lack of value on the fundamental importance of care as an activity to society. State welfare policies remain focused on promoting individual rather than collective responsibility for well-being, and promoting and valuing paid work rather than care (Watson and Mears, 1999; Lloyd, 2006b; Barnes, 2012). These trends are even revealed in the more progressive carer strategy documents. For Barnes (2012, p. 143) notes how the carer strategies advocate work as the key solution to alleviating carers' poverty risks, which gives a clear message that care-giving is not enough. Meanwhile, the paucity of the statutory support and protection provided to address care relationships' care-related risks ensures that care-giving is not awarded equal value to breadwinning. Furthermore, the needs based principles of entitlement (Fraser, 1994) attached to some elements of the care support system serves to limit state protection to low income care relationships. This has stigmatising and residualising effects (Kittay, 2001) for those in receipt of the support and excludes all care relationships from being recognised and valued.

In order to instil an ethics of care which would acknowledge the true value of care to society, Williams (2001) previously advocated for the development of a National Care Strategy covering all types of care and policy domains which would provide the basis for developing the values attached to care, such as trust, dignity, mutual respect and bodily integrity, across informal, social and professional practices of care. However this analysis has highlighted that strategies cannot in themselves create fundamental reform of policy systems. Instead the entire English policy system needs to be reconstructed in accordance with the principles of an ethics of care. This requires a fundamental shift in political and economic frameworks in order to truly recognise the importance of care to society and the need for the state to assume primary responsibility for providing rights, protection and resources to those in need of care and providing care. This will require direct connections to be made between policy-making and the practicalities and daily experience of care

relationships (Lloyd, 2010). This is what Watson and Mears (1999, p. 4) term 'policy as a lived experience', meaning that 'social policy is not just what politicians and public servants devise' but should also reflect 'how it is experienced at grass roots'. To achieve an ethics of care in practice will ultimately require the overarching care policy system to realise the reality and meaning of providing and requiring care.

## **Chapter 10: Conclusion**

This final chapter reflects upon the contribution that this study makes to the wider literature, and considers the strengths and limitations of the overarching research project. Recommendations are made about further research that could be undertaken in relation to analysing the treatment of informal care by states. With some final reflections about the English state's treatment of informal care being made to draw this thesis to a close.

### **10.1 Contributions of the study**

This research project has been a worthwhile undertaking from both a personal and academic perspective. On a personal level, undertaking this academic exploration of, and research on, informal care has enabled me to gain a more in-depth and reflexive understanding of my own caring responsibilities and experiences. The fact that care-related crises in my own life have persisted on a regular basis throughout the duration of undertaking this PhD (2010-2014) has helped to reiterate the meaningfulness and relevance of this research. Consequently this has reinforced my determination and dedication to complete my thesis despite experiencing these care-related challenges and setbacks. Meanwhile from an academic perspective I have designed and carried out a research project which has generated relevant data with which to answer my research questions, and which have enabled my thesis to make important conceptual and empirical contributions to the existing literature. These specific contributions will now go on to be discussed in more detail.

#### **10.1.1 Contributions to the social risk literature**

My thesis has made a number of significant conceptual and empirical contributions to the social risk literature. This has involved clarifying and expanding upon the conceptualisation of social risk presented in the existing literature, making a case for informal care being categorised as a social risk, and undertaking an empirical study to analyse the extent to which informal care is recognised and treated as a social risk by the English state.

My ability to make these contributions was facilitated by applying a feminist lens to undertaking a thorough examination and critique of the conceptualisation of social risk found within the existing literature. Using the feminist construction of the public-private dichotomy enabled me to expose

that the existing literature had analysed the concept of social risk from a gender biased perspective. This was revealed in the way in which the literature focused on discussing those contingencies pertaining to the sphere of paid employment which states had already recognised and provided statutory protection against, such as old age poverty, unemployment, working poverty etc. Realising this bias enabled me to expose that the existing social risk literature only defines those contingencies which the state has already taken explicit responsibility for protecting citizens against through their policies, as social risks. The identification of this restricted conceptualisation helped to explain why the existing literature had neglected to adequately recognise and discuss the contingency of informal care as a social risk. This analytical critique and revelation enabled me to make a significant theoretical contribution to the conceptualisation of social risk. I argued that a contingency can be categorised as a social risk whether or not it is recognised and treated as one by the state, so long as it contains certain characteristics. I deconstructed the concept of social risk into its key component parts in order to make the case that for a contingency to be categorised as a social risk it must present poverty *and* welfare risks to the risk-bearer; it must be a shared and predictable risk across society affecting significant numbers of people within a given population; and that certain groups may be more vulnerable to experiencing these contingencies on account of characteristics such as age, gender, relational status and class. I consequently used this conceptualisation, bolstered by the application of existing empirical evidence, to make the case that the need for care and informal care-giving are risk-based activities and contain the required characteristics for being categorised as social risks. Furthermore I argued that the risks associated with long-term care also contain a unique dimension which sets this contingency apart from other social risks. The care-related risks experienced by each member of the caring dyad are inter-related, and consequently their individual risks can impact on, and exacerbate, one another's risks.

My conceptualisation of social risk contributes a more nuanced analysis to elucidate and draw the distinction between a contingency: being a social risk; being recognised as a social risk by the state; and being treated as a social risk by the state through their policies. Part of this analytical work also entailed clarifying the factors which contribute to the process by which states come to recognise contingencies as social risks. This was subsequently applied to explaining the changing treatment of informal care by states over time, from being an unrecognised social risk during the industrial, post-war era to gradually becoming recognised as a social risk during the post-industrial era as evidenced by the array of care policies being implemented to support older people with care needs and informal care-givers. Moreover, my conceptualisation of social risk also makes a further contribution to the literature by drawing attention to the fact that even among those social risks

which are recognised by welfare states, different groups of affected risk-bearers may be treated by state policies differentially. Consequently not all affected risk-bearers are necessarily recognised and provided with social protection against the risks which they face.

My research study also makes a significant empirical contribution to the social risk literature by undertaking an empirical analysis of the English care policy system with a view to evaluating the extent to which informal care is recognised and treated as a social risk by a state in practise. Using social risk as the lens through which to analyse English care policies has enabled me to draw attention to the inconsistency with which informal care and the care-related risks experienced by different types of informal carers and older care-receivers are recognised and treated by the state. It has also helped to expose how system and actor effects may also maintain and exacerbate risk-bearers' care-related risks or produce additional secondary risks. Conducting such a thorough and nuanced analysis produced the evidence that the English state does not provide all informal carers and care relationships with adequate, predictable, and consistent, statutory protection against the care-related risks which they face. It is through exposing this inconsistent and inadequate treatment of care-related risks and risk-bearers that I have been able to conclude that informal care is recognised but not treated as a social risk by the English state.

### **10.1.2 Contributions to the care policy literature**

This thesis makes a number of empirical contributions to the care policy literature. My research has undertaken a comprehensive and in-depth analysis of the complexity of the English care policy system. This has entailed analysing all the care policies relating to informal carers and the long-term care of older people and the related institutional structures, processes and actors located within the English care policy environment. The results of this analysis provide a holistic national overview of the English state's treatment of informal care, care-givers and care relationships across policy domains, policy mechanisms, localities, and practitioners, which is not found elsewhere in the care policy literature. This analysis has also revealed the implications of this complexity. For example, by exposing the policy system as fragmented, diverse and largely discretionary it has revealed why the national carer strategies which do recognise informal care as a social risk have been ineffective in improving the statutory protection provided to care relationships. Meanwhile, undertaking such a comprehensive analysis has supported the identification of inconsistencies, gaps and risks contained within the existing statutory provision and institutional arrangements; and barriers to accessing the statutory support that is available caused by system and actor effects. This has permitted substantive conclusions to be drawn about the weakness of informal carers' entitlements in England

and their unique and marginalised position in the English policy system. The thoroughness of this analysis has also permitted the generation of a range of specific policy recommendations which the English state needs to implement in order to address these issues and deficiencies, and improve the support and protection that is provided to informal care-givers and care relationships. Finally the timing of my thesis has also provided the opportunity to reflect upon the recent reforms undertaken within the care policy environment in the employment and care services domains and consider their implications for informal carers in light of my existing findings.

### **10.1.3 Contributions to the feminist literature**

This thesis has utilised the feminist critique about the gendered construction of care and its location within the private sphere of the household to help explain its devalued and neglected position and treatment by states and the social risk literature. This thesis makes an empirical contribution to the feminist literature by extending the analysis of the English state's treatment of informal care-givers to considering how it is affected by a wide range of characteristics including age, relational status, employment status, financial circumstances, living arrangements etc. This has consequently produced useful empirical evidence about the extent to which the state recognises and manages the diversity of informal care-givers in England. This research study has also acknowledged in its design the feminist assertion about the need to recognise the inter-related nature of care. Consequently, dyadic care relationship types were formulated as the unit of analysis. This permitted the policy analysis to draw conclusions about the extent to which the English state recognises and manages the relational facet of care within the design of their care policies and institutional arrangements. Undertaking this comprehensive study of the care policy environment has also provided an opportunity to empirically test the extent to which the English state has applied the principles of an ethics of care to its treatment of informal care. With the findings providing the empirical evidence to conclude that an ethics of care is missing from the care policy system in England.

### **10.1.4 Methodological contributions**

This research project makes a number of significant methodological contributions to the use of policy simulation techniques. Instead of applying this technique to conducting a comparative cross-national study, the model care relationship matrix has been successfully used to compare the treatment of care relationship types across policy domains, localities and practitioners within a single national case study. Furthermore, several key innovations were applied to enable a policy simulation technique to be successfully adapted to undertaking a systematic analysis of the

treatment of informal care by the state. Firstly, a dyadic unit of analysis was constructed consisting of a care-receiver and care-giver. This decision reflected the importance of acknowledging within the research design that care takes place within a relationship. Moreover this innovation was required in order to enable the state's treatment of informal care to be accurately assessed. For it permitted the analysis of how states may provide support to informal carers via the care-receiver in the form of replacement care services, as well as helping to reveal how informal carers' entitlements can be contingent upon care-receivers' entitlements. It also enabled the extent to which the construction of institutional processes and policies address and manage the inter-relational nature of care to be analysed. This helped to reveal how policies can either generate conflict between members of the caring dyad, or promote the wellbeing of the care relationship as a whole. Secondly, the model care relationship tool successfully incorporated all of the care policy mechanisms contained within three policy domains, including cash benefits, care services and employment-related support. This facilitated a holistic analysis of the state's treatment of the poverty and welfare risks experienced by the caring dyad to be undertaken.

Despite the noted limitations of using policy simulation techniques discussed previously in Chapter 5, in retrospect it is possible to conclude that the use of this type of methodological tool proved to be highly suitable for enabling me to achieve my research objectives. It provided a systematic yet flexible tool for assessing the treatment of multiple types of care relationships across multiple policy domains and dimensions. It enabled me to capture the intended policy outputs different risk-bearers would be assessed to receive which enabled me to realise the state's intended treatment of informal care and expose the logics of the system in a systematic way.

## **10.2 Limitations of the study**

A number of critical reflections are required about the research project in order to acknowledge the limitations of the study.

Although the model care relationship matrices were a suitable methodological tool for achieving the research objectives, their use within the interviews undertaken with practitioners proved to be quite laborious. This was due to the number of care relationship types that had to be discussed; and the repetitious nature of the vignettes due to them being constructed around similar configurations of primary characteristics. A pilot interview conducted with a social work practitioner at the start of the fieldwork phase helped to reveal the time-consuming nature of going through each care relationship type in the numerical order used in the matrix. The order was subsequently revised so



that the care relationships grouped within each care relationship tier<sup>167</sup> were discussed consecutively. This required only the key differences between the individual vignettes in each tier to be highlighted which sped the interview process up considerably. Even so, it still took up to two hours to conduct some of the interviews. The structuring of the vignettes, matrix, and interviews would therefore require further consideration if any additional research was undertaken with busy professionals in the future. The absence of humanising details in the vignettes such as names, gender, health conditions, thoughts and feelings etc. also had the potential to be problematic, with one interviewee stating,

*'...you see the thing is....I would ask for so much more information because I would be there saying....what kind of support are they asking for, what are they still prepared to do....So its very situational....You can't actually answer things like this' (L1LAM1).*

Even so, on the whole I found that the use of vignettes prompted full and reflexive discussions by practitioners about their own practice as well as agency policies and procedures. The vignettes also prompted them to reflect upon similar cases that they had dealt with during their careers when discussing their decision-making about the type and level of statutory support they would assess each care relationship type to be entitled to receive. This provides evidence that the constructed care relationship types bore some semblance to empirical reality. However it is also important to acknowledge the exclusion of certain characteristics, such as ethnicity, from the design of my methodological tools as a further limitation of my research. This has prevented my research from exploring the extent to which these characteristics may also affect the policy outputs of care relationships on account of practitioner decision-making. Other research studies have found that informal carers from ethnic minority groups receive less recognition and statutory support than their white counterparts (Eley, 2003; Anttonen and Zechner, 2011; Carers UK, 2011a).

Decisions were made to exclude certain policy areas from the care relationship matrix. The health service was not incorporated as an additional policy domain within the matrix because individuals are not awarded statutory entitlements or rights to specific types and levels of support in this domain.<sup>168</sup> Even so, a number of interviewees spoke at length about the important role that health professionals and health services can play in relation to providing specific support to informal carers;<sup>169</sup> identifying informal carers; and raising their awareness of the support that is available by providing information. Moreover, I did not include a residential care option within the care services

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<sup>167</sup> See Figure 13.

<sup>168</sup> Other than the provision of free health care via the NHS.

<sup>169</sup> For example, annual medicals and fitness checks for informal carers were being piloted in one Primary Care Trusts (L2TS1M2), and government funding was noted to have been provided to PCT's to provide carer breaks.

matrix even though this would potentially have been a viable service option for practitioners to consider, particularly in relation to the constant care relationships. This decision was initially taken due to the focus of the thesis being on older people living in their own homes within the community. But in retrospect this may have been an erroneous oversight, because if practitioners had assessed the older people to be entitled to access this type of service option it would have indicated that the state recognises and is seeking to protect carers against the welfare risks which they face and is treating them as superseded care-givers (Twigg, 1989, 1992; 1994).

The sample of research participants did not capture certain key personnel who could also affect the caring dyad's access to statutory entitlements. For example, local authority administrators were noted to act as the initial gatekeepers for individuals gaining access to statutory support in the care services domain due to taking and screening the initial referrals (L1LAP1/L1LAP2/L2LAP1). The Commission for Social Care Inspection previously noted that these administrative staff often do not sufficiently explore people's needs and the willingness and ability of their informal carers to care, leading to people being screened out of the system too early (Department of Health, 2010a, p. 26). Moreover, in the cash benefit domain I did not interview any front-line assessors from within the various benefit agencies. Instead I relied on secondary data and research participants who occupied managerial positions to determine the care relationships' statutory entitlements in this domain. Consequently, my data are unable to analyse the extent to which the decision-making of either set of administrative workers may affect the members of the caring dyad accessing support in these domains. Moreover, the universal regulations that exist within the cash benefits policy domain are assumed, rather than proven, to significantly limit practitioner discretion and inconsistency occurring. Meanwhile, the decision was taken not to conduct interviews with employer organisations and managers who operationalise national employment legislation. This is because it would have been too time-consuming to gather enough data to meaningfully explore the treatment of employed care-givers across different employer organisations. The focus of the analysis was therefore restricted to analysing the statutory rights of employed care-givers using documentary data and the interpretations of national and local third sector specialists.

I maintain my view that undertaking interviews with informal carers and older people could not have replicated the systematic analysis of the extent to which the state protects different types of care relationships against care-related risks which was achieved using the model care relationship matrix. However, on reflection the research findings in Chapter 8 would have been enhanced by undertaking interviews with informal care-givers and older people in order to explore their

experiences of accessing statutory support. This would have provided more substantial data about their actual experiences of engaging in internal negotiations with each other; and external negotiation processes with statutory and non-statutory actors. It would also have provided first-hand accounts of the barriers they can face in gaining an awareness of the statutory support that is available and their ability to access it. Instead this element of the analysis relied upon the views and interpretations of research participants who were interviewed in their role as professionals and third sector representatives. Although some of these interviewees relayed real-life case examples as part of their responses and several research participants discussed their current or previous personal experiences of providing informal care themselves.

The generalisability of the research data also requires consideration due to the intention of this thesis to make a macro-level statement about the extent to which informal care is treated as a social risk by the English state. Although the cash benefits data and employment legislation data are viable for making national level claims about the state's treatment of care-related risks and care relationships, this claim cannot be extended to the care services and JCP domains in the same way. The decentralisation of policy implementation down to a locality level in these domains means that these data cannot be taken to be representative of the treatment of care relationships and care-related risks for the country as a whole (Eardley, 1996). These data can only be said to represent the treatment of informal carers and older people in those specific localities. Although it would have been preferable to select significantly more than two key localities in order to extend the generalisability of the findings, the additional time required to collect and analyse more data deterred me from doing so. Even so I consider that the findings generated from these localities can still represent something about the treatment of informal care at a national level. For it is the ambiguity contained within the national legislation and policy regulations together with the national drive to promote localism and agency and practitioner discretion within these policy domains that allow territorial and practitioner-based inequalities in the treatment of informal care to emerge across and within localities. Consequently, the trends of inconsistency and variation which are revealed and confirmed by the locality data can be said to provide an illustrative finding about the state's overarching treatment of informal care. It is likely that these trends would have been corroborated rather than undermined by the addition of more localities into the research sample.

### **10.3 Further research**

This research project has been a worthwhile undertaking for gaining an understanding of the treatment of informal care as a social risk in England at one specific point in time. Its successful

completion provides the incentive to consider further research being undertaken at both a national and cross-national level in order to extend the evidence base produced by this research project.

At a national level, further research could be undertaken in order to strengthen the existing research evidence generated by this project in relation to the extent of the territorial and organisational variations in the statutory support available to care relationships in England. This would constitute a worthwhile undertaking because it would provide additional data pertaining to a key social justice issue in the English case. This would require the same research to be conducted across more local authorities and JCP districts and localities. Moreover, it would also be of interest to extend the existing research to investigate the statutory and non-statutory support provided by different employers. This would help to provide more substantial data about the extent to which statutory rights to care leave and flexible working are being provided across employer organisations and the variations in the types and levels of support and protection available to working care-givers on account of where they work.

The design of my research methodology is also applicable to undertaking a longitudinal study. It would be of value to make this a longitudinal research project in order to assess the implications of the recent social care and employment reforms discussed in Chapter 9 on the statutory protection provided to care relationships. Moreover, a recent research report undertaken for the DWP also noted the ongoing possibility that the coalition government will undertake a reform of the Carers Allowance as part of their wider welfare reforms (Parker et al., 2014). It will be important to assess the impact of these reforms on the treatment of informal care as a social risk in England by reapplying this research methodology to re-assessing each care relationship's statutory entitlements in 3 to 5 years time. This time lapse would be required in order to allow for local authorities to fully implement the Care Act reforms which take effect from April 2015 onwards; and the Benefits Agency to roll out any potential changes to the benefits system. The collected data would support a comparison being undertaken between the 'current' and 'reformed' policy system and the English state's treatment of informal care as a social risk over time. The current research findings would provide a valuable baseline from which to assess whether, and to what extent, the reforms had contributed to different informal care-givers and care relationship types receiving enhanced, or improved protection from the state against the care-related risks which they experience. Undertaking this type of longitudinal analysis was considered a viable and useful undertaking by the national government interviewee (NGPR).

In terms of the generalisability of the English case study findings to other national contexts, the intricacy and specificity of case study designs do not permit research findings to be generalised beyond the boundaries of the case under investigation (Yin, 2009; Denscombe, 2010; Bryman, 2012). However, this research study does provide the opportunity for ‘analytic generalisation’ (Yin, 2009, p. 15). It has provided a viable test case for undertaking an analysis of the treatment of informal care as a social risk within a national context, and it has produced a reliable set of methodological tools which could easily be adapted to enable a similar analysis to be undertaken across other national contexts. Extending this analysis cross-nationally could add a number of comparative dimensions to the research. Research could either be undertaken in the format of additional standalone national case studies, whose results could be compared to one another in order to analyse the extent to which different states treat informal care as a social risk through their care policies. Or a more challenging comparative study could be designed which set out to compare the treatment of informal care, risk bearers and care-related risks across national contexts and explain the reasons for the differences or similarities that emerged in the treatment of these phenomena. This type of comparative analysis may consider explanatory factors such as the characteristics of long-term care found in national contexts and the presence or absence of the factors which can affect the process by which a contingency becomes recognised as a social risk discussed in Chapter 3. The comparative care regime literature noted in Chapter 4 could facilitate the case selection. Either more similar cases could be compared, for example, England could be compared to other means-tested care regimes, such as the USA, and New Zealand (Anttonen and Sipilä, 1996; Burau et al., 2007).<sup>170</sup> Or else England could be compared to divergent cases. These could include ‘Scandinavian’ public service care regimes such as Denmark, Sweden, Finland, and the Netherlands which are known to be provide higher levels of care services, and in some cases alternative types of support in the form of care wages schemes and paid care leaves etc. (Kautto, 2002; Pavolini and Ranci, 2008). Ireland, the case I had initially intended to compare to England, would also provide an interesting comparator due to its divergent positioning within the care regime literature, often categorised as falling between the Anglo-Saxon care regime type and the Southern European family care model where care responsibilities are deemed to be a private family matter (Anttonen and Sipilä, 1996; Bettio and Plantenga, 2004). Moreover, Ireland has not experienced the same demographic pressures as most other advanced capitalist countries due to its higher fertility rates, higher emigration rates and a lower proportion of older people (McLaughlin, 1994). It would therefore be interesting to explore whether divergent approaches to the treatment of informal care as a social risk emerge across both countries.

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<sup>170</sup> Although the federal nature of some states would need to be accounted for when designing the methodology.

## 10.4 Final thoughts

This thesis has undertaken a comprehensive analysis of the English state's treatment of the informal care of older people. The conclusions drawn reveal that informal care is not treated as a social risk by state care policies, with substantial numbers of informal care-givers and care-related risks remaining inadequately protected or unprotected, and the costs and risks associated with care remaining predominantly privatised to families to manage. Furthermore, this research has highlighted that the underlying culture pedalled by capitalist society, that care is a peripheral factor of human existence, remains unchallenged.

This study has been conducted at an interesting juncture in time. Global trends such as population ageing are fundamentally changing the demographic context of care and requiring states to increasingly take notice of care as a 'social problem'. The English state is responding to this challenge and taking active steps to fundamentally alter key elements of the statutory support that is provided to older people and their informal carers. Although any improvements these changes can make to the treatment of informal care are to be welcomed, the resulting outcomes have the potential to be quite limited. At a recent presentation given at the International Conference on Evidence-based Policy in Long-term Care in September 2014, researchers undertaking a study on behalf of the Department of Health noted that the government is not intending to provide additional funding to support local authorities to action *all* of the changes wrought by the Care Act 2014. Although more money is to be provided to support local authorities to deliver on their new statutory duties for informal carers (NGPR), no additional funding will be provided to manage the impact that the new eligibility criteria for care-receivers will have on widening access to an assessment of need and care and support (Marczak et al., 2014). So, despite the current government making efforts to strengthen and extend carers' rights, there is no guarantee that these improved rights will result in improved support and protection for care relationships.

Moreover, none of these reforms will bring about the fundamental changes to the system that are required for ensuring that informal care is treated as a social risk by the English state and in accordance with an ethics of care. For this to be achieved it would require states: to recognise the care-related needs and risks of all care-givers and care-receivers; provide universal and free access to support and protection to all risk-bearers; ensure that all statutory support is adequately resourced; and ensure that a comprehensive range of care options is made available which address the specific and diverse needs and risks of care relationships. These changes would require a fundamental restructuring of the care policy system to be undertaken in order to simplify

institutional structures and processes, and ensure the state assumes greater statutory responsibility for ensuring adequate and equitable support is provided to care relationships across localities, organisations, agencies and policies. In light of this thesis' findings it is clear that for now any hope of the English case achieving the feminist ideal of the activity of informal care being respected, valued and adequately supported within capitalist society, remains unfulfilled.

## Appendices

### Appendix 1: The care relationship vignettes

Key characteristics	Biography of care relationships
<p style="text-align: center; background-color: red; color: white; font-weight: bold;">Care relationship 1</p> <p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver aged over 65</li> <li>Care-giver aged between 25-60</li> </ul> <p><b>Constant care provided</b></p> <ul style="list-style-type: none"> <li>168 hrs per week</li> <li>Day and night</li> </ul> <p><b>Lowest income/savings level</b></p> <ul style="list-style-type: none"> <li>Care-giver: no income</li> <li>Care-receiver receives a Basic State Pension</li> <li>Household savings below £6,000</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had mental and physical health problems for several years. Due to their deteriorating condition they now require frequent help with managing all of their personal care needs throughout the day and at night including washing, dressing, using the toilet, assistance with eating, drinking and taking their medication. They need physical assistance with their mobility and cannot get in and out of bed without physical support. They also require help with all domestic tasks including preparing their meals and managing the household and their finances.</p> <p><b>Personal circumstances:</b> The care-receiver lives with their son/daughter who is single and who provides them with all their care support as and when required 24 hours a day. The care-receiver is unsafe to be left alone in the house meaning that their son/daughter is unable to go out unless someone else comes to sit with them. The son/daughter is under pension age but is unable to work due to providing care full-time.</p> <p><b>Financial circumstances:</b> The son/daughter has no source of income. The care-receiver is in receipt of a Basic State Pension worth up to £107.45 per week but has no other source of income. Both have savings under £6,000. They live in a rented property. The care-receiver and care-giver are joint tenants.</p>
<p style="text-align: center; background-color: yellow; color: black; font-weight: bold;">Care relationship 2</p> <p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver aged over 65</li> <li>Care-giver aged between 25-60</li> </ul> <p><b>Daily care provided</b></p> <ul style="list-style-type: none"> <li>35 hrs per week</li> <li>During the day</li> </ul> <p><b>Lowest income/savings level</b></p> <ul style="list-style-type: none"> <li>Care-giver: no income</li> <li>Care-receiver receives a Basic State Pension</li> <li>Each person has savings below £6,000</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had a physical health problem for a number of years. Due to their health condition they have limited mobility and require assistance with managing their personal care including washing and dressing/undressing. However, they are able to eat and drink without assistance and can manage to use the toilet independently. They require support with managing all domestic tasks. The care-receiver is safe to be left alone for periods of time during the day and overnight.</p> <p><b>Personal circumstances:</b> The care-receiver lives alone and receives care from their single son/daughter who lives in a separate household in the local vicinity. The son/daughter provides 35 hours of care support every week. They visit at least 3 to 4 times every day to help their parent with getting up in the morning, preparing their lunch and tea and getting ready for bed in the evening. In addition they do the laundry, housework, shopping and help to manage the household and finances. They also accompany their parent to medical appointments and to visit friends/relatives and attend other social events. The son/daughter is under pension age but does not work due to providing care full-time.</p> <p><b>Financial circumstances:</b> The son/daughter has no source of income. The care-receiver is in receipt of a Basic State Pension worth up to £107.45 per week but has no other source of income. Both have savings under £6,000. They both live in rented properties.</p>



	Key characteristics	Biography of care relationships
Care relationship 3	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver aged over 65</li> <li>Care-giver aged between 25-60</li> </ul> <p><b>Weekly care provided</b></p> <ul style="list-style-type: none"> <li>16 hrs per week</li> <li>During the day</li> </ul> <p><b>Lowest income/savings level</b></p> <ul style="list-style-type: none"> <li>Care-giver: no income</li> <li>Care-receiver receives a Basic State Pension</li> <li>Each person has savings below £6,000</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had a physical health problem for a number of years. They are able to manage their personal care themselves and can prepare their own meals. However, they require support on a weekly basis with doing their shopping, housework, laundry and managing their medication, household maintenance and finances. They also need support to access social activities and attend any medical appointments. They are beginning to require someone to be on hand in the household to monitor their safety with getting in and out of the bath once or twice a week.</p> <p><b>Personal circumstances:</b> The care-receiver lives alone and receives support from their single son/daughter who lives in a separate household in the local vicinity. The son/daughter provides 16 hours of care support every week consisting of a number of visits as and when required. The son/daughter is under pension age and is not currently working but would like to find some part-time employment.</p> <p><b>Financial circumstances:</b> The son/daughter has no source of income. The care-receiver is in receipt of a Basic State Pension worth up to £107.45 per week but has no other source of income. Both have savings under £6,000. They both live in rented properties.</p>
Care relationship 4	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver and care-giver aged over 65</li> </ul> <p><b>Constant care provided</b></p> <ul style="list-style-type: none"> <li>168 hrs per week</li> <li>Day and night</li> </ul> <p><b>Lowest income/savings level</b></p> <p>The couple;</p> <ul style="list-style-type: none"> <li>receive Basic State Pensions</li> <li>have no other income</li> <li>have joint savings below £6,000</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had mental and physical health problems for several years. Due to their deteriorating condition they now require frequent help with managing all of their personal care needs throughout the day and at night including washing, dressing, using the toilet, assistance with eating, drinking and taking their medication. They need physical assistance with their mobility and cannot get in and out of bed without physical support. They also require help with all domestic tasks including preparing their meals and managing the household and their finances.</p> <p><b>Personal circumstances:</b> The care-receiver lives with their husband/wife who is also aged over 65 and retired. The husband/wife provides them with all their care support as and when required 24 hours a day. They are unable to go out unless someone else comes to sit with their spouse who is unsafe to be left alone in the house.</p> <p><b>Financial circumstances:</b> The husband is in receipt of a Category A Basic State Pension worth up to £107.45 per week based on his NI contribution record. The wife is in receipt of a Category B Basic State Pension worth up to £64.40 per week based on her husband's NI contribution record. They have no other sources of income and joint savings under £6,000. They live in a rented property.</p>
Care relationship 5	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver and care-giver aged over 65</li> </ul> <p><b>Daily care provided</b></p> <ul style="list-style-type: none"> <li>35 hrs per week</li> <li>During the day</li> </ul> <p><b>Lowest income/savings level</b></p> <p>The couple;</p> <ul style="list-style-type: none"> <li>receive Basic State Pensions</li> <li>have no other income</li> <li>have joint savings below £6,000</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had a physical health problem for a number of years. Due to their health condition they have limited mobility and require assistance with managing their personal care including washing and dressing/undressing. However, they are able to eat and drink without assistance and can manage to use the toilet independently. They require support with managing all domestic tasks. The care-receiver is safe to be left alone for periods of time during the day and overnight.</p> <p><b>Personal circumstances:</b> The care-receiver lives with their husband/wife who is also aged over 65 and retired. The husband/wife provides them with 35 hours of care support every week. They support their spouse to get up in the morning and ready for bed in the evening and prepare all of their meals. They do the laundry, housework, shopping, manage the household and their joint finances. They also accompany their spouse to medical appointments and to visit their friends/relatives and attend other social events.</p> <p><b>Financial circumstances:</b> The husband is in receipt of a Category A Basic State Pension worth up to £107.45 per week based on his NI contribution record. The wife is in receipt of a Category B Basic State Pension worth up to £64.40 per week based on her husband's NI contribution record. They have no other sources of income and joint savings under £6,000. They live in a rented property.</p>

	Key characteristics	Biography of care relationships
Care relationship 6	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver and care-giver aged over 65</li> </ul> <p><b>Weekly care provided</b></p> <ul style="list-style-type: none"> <li>16 hrs per week</li> <li>During the day</li> </ul> <p><b>Lowest income/savings level</b></p> <p>Each person;</p> <ul style="list-style-type: none"> <li>receives a Basic State Pension</li> <li>has no other income</li> <li>has savings below £6,000</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had a physical health problem for a number of years. They are able to manage their personal care themselves and can prepare their own meals. However, they require support on a weekly basis with doing their shopping, housework, laundry and managing their medication, household maintenance and finances. They also need support to access social activities and attend any medical appointments. They are beginning to require someone to be on hand in the household to monitor their safety with getting in and out of the bath once or twice a week.</p> <p><b>Personal circumstances:</b> The care-receiver is single and lives alone. They receive support from their sibling/friend/neighbour who is also aged over 65, retired, single, and lives in a separate household nearby. They provide 16 hours of care support every week consisting of a number of visits as and when required.</p> <p><b>Financial circumstances:</b> Both the care-receiver and care-giver are in receipt of a Basic State Pension worth up to £107.45 per week. They have no other source of income. Both have savings under £6,000. They both live in rented properties.</p>
Care relationship 7	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver aged over 65</li> <li>Care-giver aged between 25-60</li> </ul> <p><b>Constant care provided</b></p> <ul style="list-style-type: none"> <li>168 hrs per week</li> <li>Day and night</li> </ul> <p><b>Lower income/savings level</b></p> <ul style="list-style-type: none"> <li>Care-giver's net income = £203.73 per week</li> <li>Care-receiver's net income = £186.45 per week (Cat A Basic State Pension and occupational pension)</li> <li>Each person has £16,000 in savings</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had mental and physical health problems for several years. Due to their deteriorating condition they now require frequent help with managing all of their personal care needs throughout the day and at night including washing, dressing, using the toilet, assistance with eating, drinking and taking their medication. They need physical assistance with their mobility and cannot get in and out of bed without physical support. They also require help with all domestic tasks including preparing their meals and managing the household and their finances.</p> <p><b>Personal circumstances:</b> The care-receiver lives with their son/daughter who is single. The son/daughter came to live with their parent in order to provide them with care support as and when required 24 hours a day. The care-receiver is unsafe to be left alone in the house meaning that their son/daughter is unable to go out unless someone else comes to sit with them. The son/daughter is under pension age but is unable to work due to providing care full-time.</p> <p><b>Financial circumstances:</b> The son/daughter is in receipt of a net income of £203.73 per week. This income comes from renting out their property which they own. The care-receiver has a net income of £186.45 per week. This consists of a Category A Basic State Pension (£107.45) and an occupational pension (£79). Both have £16,000 in savings. The care-receiver owns the property they are currently both living in.</p>

	Key characteristics	Biography of care relationships
Care relationship 8a	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver aged over 65</li> <li>Care-giver aged between 25-60</li> </ul> <p><b>Daily care provided</b></p> <ul style="list-style-type: none"> <li>35 hrs per week</li> <li>During the day</li> </ul> <p><b>Lower income/savings level</b></p> <ul style="list-style-type: none"> <li>Care-giver's net income = £203.73 per week Working 16 hours per week</li> <li>Care-receiver's net income = £186.45 per week (Cat A Basic State Pension and occupational pension)</li> <li>Each person has £16,000 in savings</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had a physical health problem for a number of years. Due to their health condition they have limited mobility and require assistance with managing their personal care including washing and dressing/undressing. However, they are able to eat and drink without assistance and can manage to use the toilet independently. They require support with managing all domestic tasks. The care-receiver is safe to be left alone for periods of time during the day and overnight.</p> <p><b>Personal circumstances:</b> The care-receiver lives alone and receives care from their single son/daughter who lives in a separate household in the local vicinity. The son/daughter provides 35 hours of care support every week. They visit at least 3 to 4 times every day to help their parent with getting up in the morning, preparing their lunch and tea and getting ready for bed in the evening. In addition they do the laundry, housework, shopping and help to manage the household and finances. They also accompany their parent to medical appointments and to visit friends/relatives and attend other social events. The son/daughter is under pension age and works part-time, fitting their care visits around their working hours.</p> <p><b>Financial circumstances:</b> The son/daughter is in receipt of a net income of £203.73 per week (£228 gross), giving them an annual net salary of £10,594.12 (£11,856.00 gross). They work 16 hours per week in an associate professional or technical occupation, earning £14.25 per hour. This is the rate of pay for a chiropodist, IT technician, or plumber. The care-receiver has a net income of £186.45 per week. This consists of a Category A Basic State Pension (£107.45) and an occupational pension (£79). Both have £16,000 in savings. They both own the properties they live in.</p>
Care relationship 8b	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver aged over 65</li> <li>Care-giver aged between 25-60</li> </ul> <p><b>Daily care provided</b></p> <ul style="list-style-type: none"> <li>35 hrs per week</li> <li>During the day</li> </ul> <p><b>Lower income/savings level</b></p> <ul style="list-style-type: none"> <li>Care-giver has no income</li> <li>Care-giver's spouse's net income = £412.07 per week</li> <li>Care-receiver's net income = £186.45 per week (Cat A Basic State Pension and occupational pension)</li> <li>Each household has £16,000 in savings</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had a physical health problem for a number of years. Due to their health condition they have limited mobility and require assistance with managing their personal care including washing and dressing/undressing. However, they are able to eat and drink without assistance and can manage to use the toilet independently. They require support with managing all domestic tasks. The care-receiver is safe to be left alone for periods of time during the day and overnight.</p> <p><b>Personal circumstances:</b> The care-receiver lives alone and receives care from their married son/daughter who lives in a separate household in the local vicinity. The son/daughter provides 35 hours of care support every week. They visit at least 3 to 4 times every day to help their parent with getting up in the morning, preparing their lunch and tea and getting ready for bed in the evening. In addition they do the laundry, housework, shopping and help to manage the household and finances. They also accompany their parent to medical appointments and to visit friends/relatives and attend other social events. The son/daughter is under pension age and does not work due to their caring role. Their spouse works full-time.</p> <p><b>Financial circumstances:</b> The son/daughter has no source of independent income. Their spouse is in receipt of a net income of £412.07 per week (£534.38 gross), giving them an annual net salary of £21,427.54 (£27,787.50 gross). Their spouse works 37.5 hours per week in an associate professional or technical occupation, earning £14.25 per hour. This is the rate of pay for a chiropodist, IT technician, or plumber. The care-receiver has a net income of £186.45 per week. This consists of a Category A Basic State Pension (£107.45) and an occupational pension (£79). Both households have £16,000 in savings. They both own the properties they live in.</p>

	Key characteristics	Biography of care relationships
Care relationship 9	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver aged over 65</li> <li>Care-giver aged between 25-60</li> </ul> <p><b>Weekly care provided</b></p> <ul style="list-style-type: none"> <li>16 hrs per week</li> <li>During the day</li> </ul> <p><b>Lower income/savings level</b></p> <ul style="list-style-type: none"> <li>Care-giver's net income = £203.73 per week Working 37.5 hours per week</li> <li>Care-receiver's net income = £186.45 per week (Cat A Basic State Pension and occupational pension)</li> <li>Each person has £16,000 in savings</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had a physical health problem for a number of years. They are able to manage their personal care themselves and can prepare their own meals. However, they require support on a weekly basis with doing their shopping, housework, laundry, managing their medication, household maintenance and finances. They also need support to access social activities and attend any medical appointments. They are beginning to require someone to be on hand in the household to monitor their safety with getting in and out of the bath once or twice a week.</p> <p><b>Personal circumstances:</b> The care-receiver lives alone and receives support from their single son/daughter who lives in a separate household in the local vicinity. The son/daughter provides 16 hours of care support every week consisting of a number of visits as and when required. The son/daughter is under pension age and is working full-time.</p> <p><b>Financial circumstances:</b> The son/daughter is in receipt of a net income of £203.73 per week, (£228 gross), giving them an annual net salary of £10,594.12 (£11,856.00 gross). They work 37.5 hours per week in a sales and customer service or elementary occupation, earning the minimum wage of £6.08 per hour. This is the rate of pay of a retail sales assistant or tyre, exhaust and windscreen fitter. The care-receiver has a net income of £186.45 per week. This consists of a Category A Basic State Pension (£107.45) and an occupational pension (£79). Both have £16,000 in savings. They both own the properties they live in</p>
Care relationship 10	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver and care-giver aged over 65</li> </ul> <p><b>Constant care provided</b></p> <ul style="list-style-type: none"> <li>168 hrs per week</li> <li>Day and night</li> </ul> <p><b>Lower income/savings level</b></p> <p>The couple have;</p> <ul style="list-style-type: none"> <li>a joint net income = £311.00 per week (Husband: Cat A Basic State Pension plus occupational pension; Wife: Cat B state pension)</li> <li>£16,000 in joint savings</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had mental and physical health problems for several years. Due to their deteriorating condition they now require frequent help with managing all of their personal care needs throughout the day and at night including washing, dressing, using the toilet, assistance with eating, drinking and taking their medication. They need physical assistance with their mobility and cannot get in and out of bed without physical support. They also require help with all domestic tasks including preparing their meals and managing the household and their finances.</p> <p><b>Personal circumstances:</b> The care-receiver lives with their husband/wife who is also aged over 65 and retired. The husband/wife provides them with all their care support as and when required 24 hours a day. They are unable to go out unless someone else comes to sit with their spouse who is unsafe to be left alone in the house.</p> <p><b>Financial circumstances:</b> The husband is in receipt of a Category A Basic State Pension of £107.45 per week based on his full NI contribution record. The wife is in receipt of a Category B Basic State Pension of £64.40 per week based on her husband's NI contribution record. In addition the husband receives an occupational pension of £166 per week. This gives them a joint net income of £311.00 per week (£337.85 gross). They have £16,000 in joint savings and they own the property they live in.</p>

	Key characteristics	Biography of care relationships
Care relationship 11	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver and care-giver aged over 65</li> </ul> <p><b>Daily care provided</b></p> <ul style="list-style-type: none"> <li>35 hrs per week</li> <li>During the day</li> </ul> <p><b>Lower income/savings level</b></p> <p>The couple have;</p> <ul style="list-style-type: none"> <li>a joint net income = £311.00 per week (Husband: Cat A Basic State Pension plus occupational pension; Wife: Cat B state pension)</li> <li>£16,000 in joint savings</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had a physical health problem for a number of years. Due to their health condition they have limited mobility and require assistance with managing their personal care including washing and dressing/undressing. However, they are able to eat and drink without assistance and can manage to use the toilet independently. They require support with managing all domestic tasks. The care-receiver is safe to be left alone for periods of time during the day and overnight.</p> <p><b>Personal circumstances:</b> The care-receiver lives with their husband/wife who is also aged over 65 and retired. The husband/wife provides 35 hours of care support every week. They support their spouse to get up in the morning, ready for bed in the evening and prepare all of their meals. They do the laundry, housework, shopping, manage the household and their joint finances. They also accompany their spouse to medical appointments and to visit their friends/relatives and attend other social events.</p> <p><b>Financial circumstances:</b> The husband is in receipt of a Category A Basic State Pension of £107.45 per week based on his full NI contribution record. The wife is in receipt of a Category B Basic State Pension of £64.40 per week based on her husband's NI contribution record. In addition the husband receives an occupational pension of £166 per week. This gives them a joint net income of £311.00 per week (£337.85 gross). They have £16,000 in joint savings and they own the property they live in.</p>
Care relationship 12	<p><b>Age</b></p> <ul style="list-style-type: none"> <li>Care-receiver and care-giver aged over 65</li> </ul> <p><b>Weekly care provided</b></p> <ul style="list-style-type: none"> <li>16 hrs per week</li> <li>During the day</li> </ul> <p><b>Lower income/savings level</b></p> <p>Each person has;</p> <ul style="list-style-type: none"> <li>a net income = £186.45 per week (Cat A Basic State Pension and occupational pension)</li> <li>£16,000 in savings</li> </ul>	<p><b>Care requirements:</b> The care-receiver has had a physical health problem for a number of years. They are able to manage their personal care themselves and can prepare their own meals. However, they require support on a weekly basis with doing their shopping, housework, laundry, managing their medication, household maintenance and finances. They also need support to access social activities and attend any medical appointments. They are beginning to require someone to be on hand in the household to monitor their safety with getting in and out of the bath once or twice a week.</p> <p><b>Personal circumstances:</b> The care-receiver is single and lives alone. They receive support from their sibling/friend/neighbour who is also aged over 65, retired, single, and lives in a separate household nearby. They provide 16 hours of care support every week consisting of a number of visits as and when required.</p> <p><b>Financial circumstances:</b> Both the care-giver and the care-receiver has a net income of £186.45 per week. This consists of a Category A Basic State Pension of £107.45 and an occupational pension of £79. Each person has £16,000 in savings and owns the property they live in.</p>

## Appendix 2: Supplementary interview questions for social workers

<b>Process of accessing support via Social Services</b>
What is the process by which an informal care-giver of an older person would access support from social services?
Carers are entitled to a Carer Assessment if they provide a 'regular and substantial amount of care'. How does LA1 define this?
How would you decide whether a carer should be offered a: <ul style="list-style-type: none"> <li>• Carer Assessment</li> <li>• Or that their needs should be assessed as part of the older persons Community Care Assessment?</li> </ul>
Can carers access different types or levels of support depending on the type of assessment they have had?
Have your own personal experiences of providing informal care affected the way in which you recognise or undertake assessments of carer's needs?
If the older person in need of care refuses to have an assessment of their needs or refuses care services, what guidance does LA1 issue about how the carer can be best supported?

<b>Eligibility criteria for services (FACS)</b>
What eligibility band does an older person need to fit in order to be eligible for care services?
What eligibility band does a care-giver need to fit in order to be eligible for care services?
Have there been any changes to eligibility criteria or service provision levels as a result of government cuts?
Which of the following factors would be taken into account when making decisions about eligibility levels?
Which factor is more important in deciding how much help a person can access?
Gender of care-giver or care receiver
Age of care-giver or care-receiver
State of health of care-giver or care receiver
Level of stress experienced by care-giver
Number of hours of care provided by the care-giver
Employment status of care-giver
Would carers who are working or who want to go out to work get more help?
Quality of relationship between the carer and older person?

<b>Does the following list capture all the services which are available to support carers in LA1?</b>
<b>Home Support</b>
Can carers receive help with domestic tasks if they want to continue undertaking personal care for the older person?
<b>Short stays in residential care homes</b>
Is there a limit on how many weeks respite can be provided over the period of a year?
<b>Day sitting services</b>
Are the Carer Breaks provided by Crossroads the only sitting service available to carers?
Can the Crossroad carers undertake help with domestic tasks whilst sitting with the cared for person?
<b>Night sitting services</b>
<b>Day care</b>
<b>Telecare</b>
<b>Community Alarms</b>

<b>Meal services</b>
<b>Incontinence Laundry services</b>
<b>Equipment and Aids for the older person</b>
<b>Transport costs</b> Does LA1 offer financial support with: Discounts on buses for carers? Is Ring and Ride funded by the council? Is the Volunteer Driver scheme available to carers?
<b>Carers Response Emergency Support Service</b> Is this only available to carers who have had a Carer Assessment? Is there a limit on how many times a year the service can be used?
<b>Are these carer information and support services funded by LA1?</b> Carers Centre The Alzheimer's Society
<b>Training for carers</b> What training is available for carers? Is it only available to carers who have had a Carer Assessment? Are carers entitled to discounts on leisure services in LA1?
<b>Do funding applications for all these services have to go via panel?</b> Are recent budget cuts affecting; <ul style="list-style-type: none"> <li>the eligibility criteria relating to carers or the older people they care for?</li> <li>the level of service provision provided?</li> </ul>

<b>Direct Payments</b> Can Direct Payments be used by carers to pay for the following? How much can they get? Is it payable each year or do separate applications have to be made for each one? Financial support to go on holiday (with/without the care-receiver) Replacement care - short breaks Support with domestic tasks Transport costs e.g. driving lessons, petrol, repairs, and taxis Leisure activities e.g. gym subscription, classes, etc Equipment /replace furniture/white goods Can carers be offered Direct Payments which are paid weekly to purchase services and support for themselves? In your experience do many carers take the Direct Payment option? Are younger carers more likely to take on a DP than older carers?
<b>Direct Payments for the older person requiring care</b> Do many older people take the Direct Payment option? Under what circumstances can the older person use their direct payment to pay their informal carer? If the older person is using their direct payment to pay their carer does the carer lose their entitlement to a Carer Assessment?

<b>Financial assessments</b> Are carers exempt from being charged for receiving care services? If a carer has savings over £23,500/high income would they still be entitled to carer support services?
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### Appendix 3: List of research participants

Locality 1			L1	Locality 2			L2
Local Authority			LA1	Local Authority			LA2
1	Manager Operational/ Generic	Interviewed as representative of Resource Allocation Panel for older people	L1LAM1	11	Manager Operational/ Generic	Interviewed as representative of Resource Allocation Panel for older people	L2LAM1
2	Manager Strategic/ Specialist	Questionnaire completed as strategic lead for carers for the local authority	L1LAM2	12	Manager Strategic and Operational Specialist	Interviewed as; <ul style="list-style-type: none"> <li>• strategic lead for carers for the local authority</li> <li>• manager of resource allocation process for carers</li> </ul>	L2LAM2
3	Manager Operational/ Specialist	Interviewed as; <ul style="list-style-type: none"> <li>• manager of resource allocation process for carers</li> <li>• practitioner who conducts Carers Assessments</li> </ul>	L1LAM3	13	Third sector organisation 1 Manager Operational	Interviewed as operational manager who conducts Carers Assessments on behalf of local authority	L2TS1M1
4	Practitioners Generic Social Workers	Each interviewed as practitioners who assess the needs of carers and older people	L1LAP1	14	Practitioner Generic	Interviewed as; <ul style="list-style-type: none"> <li>• practitioner who assesses the needs of older people</li> <li>• representative of a Resource Allocation Panel for older people</li> </ul>	L2LAP1 <sup>1</sup>
5			L1LAP2	15	Practitioner Generic	Interviewed as practitioner who assesses the needs of older people	L2LAP2
6			L1LAP3	16	Practitioner Generic plus specialist role	Interviewed as; <ul style="list-style-type: none"> <li>• Occupational Therapist who assesses the needs of older people</li> <li>• Carers champion in locality team</li> </ul>	L2LAP3 <sup>2</sup>



Locality 1			L1	Locality 2			L2
Third sector			L1TS	Third sector			L2TS
7	Third Sector Organisation 1 Manager Strategic and operational	Interviewed as strategic and operational manager for specialist carers organisation	L1TS1M	17	Third sector organisation 1 Manager Strategic	Interviewed as strategic manager for specialist carers organisation	L2TS1M2
8	Third Sector Organisation 2 Manager Operational	Interviewed as operational manager for specialist carers organisation	L1TS2M				
JobCentre Plus			JCP1	JobCentre Plus			JCP2
9	District level Manager Strategic/ Specialist	Questionnaire completed as strategic and operational manager for carers	L1JCM1	18	District level Manager Strategic/ Specialist	Questionnaire completed as strategic manager for carers	L2JCM1
10	Practitioner Specialist	Interviewed as practitioner who works with Income Support recipients (including carers)	L1JCP1	19	Practitioner Specialist	Interviewed as practitioner who works with Income Support recipients (including carers)	L2JCP1

Locality 3			L3
Local authority			LA3
20	Practitioner Generic Social Worker	Interviewed as practitioner who assesses the needs of carers and older people	L3LAP1

<b>National Level Interviews</b>			
<b>Benefits</b>			<b>B</b>
<b>21</b>	Third sector organisation Benefits advisor (Generic)	Interviewed as an expert on the benefit entitlements of carers and older people	BTSP1
<b>22</b>	DWP <sup>3</sup> Operational Manager Specialist Team	Questionnaire completed as operational manager for Carers Allowance Unit	BDWPM1
<b>23</b>	DWP Strategic Manager Specialist Team	Questionnaire completed as strategic manager at the DWP which includes a specialist remit for carers	BDWPM2
<b>Employment</b>			<b>E</b>
<b>24</b>	Third sector organisation Strategic Manager	Interviewed as a national strategic manager and expert in carers' employment legislation	ETSM1
<b>National Policy</b>			<b>P</b>
<b>25</b>	National Government Representative Strategic and Specialist	Interviewed as a national government policy representative on carers in the Department of Health	NGPR
<b>26</b>	Third Sector Organisation Representative Strategic and Specialist	Interviewed as a policy representative for a national third sector organisation specialising in carers	NTSPR

*Notes:*

<sup>1</sup> Local authority practitioners (L2LAP1 and L2LAP2) were interviewed together at their request.

<sup>2</sup> No matrix completed for L2LAP3.

<sup>3</sup> Department for Work and Pensions.

### Appendix 4: Cash benefits matrix results for care-receivers' and care-givers' entitlements

Care-relationship type			Cash Benefits										Passported benefits Paid to care-receiver and care-giver						
Financial circumstances	Age of care-giver	Level of Need/ Care provided	Care relationship	Cash transfer paid to Care-receiver			Cash transfers paid to care-giver							Entitlement holder (CR/CG)	Housing costs		Health-related costs (HRC)	Heating costs	
				Non-contrib. Disability Allowances	Means-tested benefits with disability additions		Non-contrib. Care Allowances	Means-tested benefits with carer additions					Personal Allowances incl. carer premium		Pension Credit: GC <sup>1a</sup> SC <sup>1b</sup>	Housing Benefit (HB) <sup>2</sup>			Council Tax Benefit (CTB) Council Tax reductions <sup>3</sup>
								Under pension age			Over pension age								
				Attendance Allowance	Personal Allowances incl. severe disability addition	Pension Credit: GC <sup>1a</sup> SC <sup>1b</sup>	Carers Allowance	Personal Allowances incl. carer premium	Income Support	Job Seekers Allowance	Working Tax Credit	Personal Allowances incl. carer premium	Pension Credit: GC <sup>1a</sup> SC <sup>1b</sup>						
Lowest income/savings	Below pension age (25-60)	Constant 168 hrs	1	Higher rate £77.45	£142.70 (no SDA)	at least £35.25 (GC) No SC	£58.45	£71 + £32.60 = £103.60	£45.15	0	0	N/a <sup>7</sup>	0	CR	Full HB	Full CTB	All HRC	WFP (ER) CWP WHD (CG)	
				Lower rate £51.85	£142.70 (no SDA)	at least £35.25 (GC) No SC	£58.45	£71 + £32.60 = £103.60	£45.15	0	0	N/a	0	CG	Full HB	Full CTB	All HRC	WFP n.e. CWP n.e. WHD BG 2/5	
		Daily 35 hrs	2	Lower rate £51.85	£142.70 (no SDA)	at least £35.25 (GC) No SC	£58.45	£71 + £32.60 = £103.60	£45.15	0	0	N/a	0	CR	Full HB	Full CTB	All HRC	WFP (ER) CWP WHD (CG)	
				Lower rate £51.85	£142.70 (no SDA)	at least £35.25 (GC) No SC	£58.45	£71 + £32.60 = £103.60	£45.15	0	0	N/a	0	CG	Full HB	Full CTB	All HRC	WFP n.e. CWP n.e. WHD BG 2/5	
		Weekly 16 hrs	3	0	£142.70 (no SDA)	at least £35.25 (GC) No SC	0	£71	0	£71	0	N/a	0	CR	Full HB	Full CTB	All HRC	WFP (ER) CWP WHD (CG)	
				0	£142.70 (no SDA)	at least £35.25 (GC) No SC	0	£71	0	£71	0	N/a	0	CG	Full HB	Full CTB	All HRC	WFP (ER) CWP WHD (CG)	

														CG	Full HB	Full CTB	All HRC	WFP n.e CWP n.e. WHD BG 2/5
	Above pension age (65+)	Constant 168 hrs	4	Higher rate £77.45	Calculated as couple	See care- giver findings	Underlying entitlement	N/a	0	0	0	£217.90 + £32.60 = £250.50	At least £78.65 (GC) No SC	CR and CG	Full HB	Full CTB	All HRC	WFP (ER) CWP WHD (CG)
		Daily 35 hrs	5	Lower rate £51.85	Calculated as couple	See care- giver findings	Underlying entitlement	N/a	0	0	0	£217.90 + £32.60 = £250.50	At least £78.65 (GC) No SC	CR and CG	Full HB	Full CTB	All HRC	WFP (ER) CWP WHD (CG)
		Weekly 16 hrs	6	0	£142.70 (no SDA)	at least £35.25 (GC) No SC	0	N/a	0	0	0	£142.70 (no Carer addition)	at least £35.25 (GC) No SC	CR	Full HB	Full CTB	All HRC	WFP (ER) CWP WHD (CG)
Lower income/savings	Below pension age (25-60)	Constant 168 hrs	7	Higher rate £77.45	£142.70 (no SDA)	No GC No SC	£58.45	N/a	0	0	0	N/a	0	CR	n/a	Exemption SMI DBR	P, E (age) G, D, T, n.e.	WFP (LR) CWP n.e. WHD BG n.e
		Daily 35 hrs (Single)	8a 9	Lower rate £51.85	£142.70 + £58.20 = £200.90	£2.45 (GC) £18.54 (SC)	0	N/a	0	0	0	N/a	0	CG	n/a	Reduction CR	P, E, G, D, T n.e.	WFP n.e. CWP n.e. WHD BG n.e.
														CR	n/a	Full CTB	All HRC	WFP (ER) CWP WHD (CG)

													CG	n/a	Reduction SPR	P, E, G, D, T n.e. T (with CR)	WFP n.e. CWP n.e. WHD BG 1/5
	Daily 35 hrs Married	8b	Lower rate £51.85	£142.70 (no SDA)	No GC No SC	£58.45	N/a	0	0	0	N/a	0	CR	n/a	Reduction SPR DBR	P, E (age) G, D, T, n.e.	WFP (LR) CWP n.e. WHD BG 2/5
													CG	n/a	n.e.	P, E, G, D, T n.e.	WFP n.e. CWP n.e. WHD BG n.e.
	Weekly 16 hrs	9	0	£142.70 (no SDA)	No GC No SC	0	N/a	0	0	£9.08	N/a	0	CR	n/a	Reduction SPR	P, E (age) G, D, T, n.e.	WFP (LR) CWP n.e. WHD BG 2/5
													CG	n/a	Reduction SPR	P, E, G, D, T n.e.	WFP n.e. CWP n.e. WHD BG 2/5
Above pension age (65+)	Constant 168 hrs	10	Higher rate £77.45	Calculated as couple	See care-giver findings	Underlying entitlement	N/a	0	0	0	£217.90 + £32.60 = £250.50	No GC No SC	CR and CG	n/a	Exemption SMI DBR	P, E (age) G, D, T, n.e.	WFP (LR) CWP n.e. WHD BG n.e.
															Reduction SPR CR n.e.		
	Daily 35 hrs	11	Lower rate £51.85	Calculated as couple	See care-giver findings	Underlying entitlement	N/a	0	0	0	£217.90 + £32.60 = £250.50	No GC No SC	CR and CG	n/a	Reduction DBR	P, E (age) G, D, T, n.e.	WFP (LR) CWP n.e. WHD BG n.e.

		Weekly 16 hrs	12	0	£142.70 (no SDA)	No GC No SC	0	N/a	0	0	0	£142.70 (no carer addition)	No GC No SC	CR	n/a	Reduction SPR DBR <i>n.e.</i>	P, E (age) G, D, T, <i>n.e</i>	WFP (LR) CWP <i>n.e.</i> WHD BG 2/5
														CG	n/a	Reduction SPR CR <i>n.e.</i>	P, E (age) G, D, T, <i>n.e</i>	WFP (LR) CWP <i>n.e.</i> WHD BG 2/5

**Source:**

Primary data collected from: BTSP1, L1JCP1, BDWPM1. Sources of secondary data include: (Child Poverty Action Group, 2012), Turn2us benefits calculator (Turn2us, 2012), health data (NHS Business Services Authority, 2008a,b,c; NHS, 2009; Directgov, 2012l,m), energy data (British Gas, 2012; eDF Energy, 2012; E.ON, 2012; npower, 2012; Scottish Power, 2012; Directgov, 2012p).

**Note:**

<sup>1a</sup> GC Guarantee Credit

<sup>1b</sup> SC Savings Credit

<sup>2</sup> Mortgage Support Payments (MSP) not calculated.

<sup>3</sup> Council Tax Benefit (CTB): SPR Single Person Reduction; CR Carer reduction; SMI Severe Mental Impairment: DBR Disabled Band Reduction Scheme.

<sup>4</sup> Winter Fuel Payment (WFP) (ER) Enhanced rate due to being on Pension Credit. LR Lower rate for those not entitled to Pension Credit

<sup>5</sup> Cold Weather Payment (CWP)

<sup>6</sup> Warm Home Discount (WHD): CG (Core Group): BG (Broader Group)

<sup>7</sup> n/a: not applicable

<sup>8</sup> *n.e.*: no entitlement

<sup>9</sup> There are two possible benefit outcomes for CR8a. Option one is recorded in the matrix: the care-receiver in receipt of the severe disability premium (£58.20) (due to being in receipt of Attendance Allowance and living alone) giving them a personal allowance of £200.90. This would provide them with an entitlement to Guarantee Credit worth £93.45. However the care-giver in this scenario is not entitled to receive a carers premium as part of their personal allowances due to the care-receiver's SDA and Carer's Allowance being mutually exclusive 'benefits'. Option 2 would involve the care-giver claiming Carers Allowance which would mean that the care-receiver would not be entitled to receive the severe disability premium which would result in them not being entitled to any means-tested benefits because their income would be above the normal personal allowance threshold of £142.70.

## Appendix 5: Care services matrix results for care-receivers' entitlements in LA2

Care relationship type				Care-Recipients' Rights				Services provided to the care-receiver (weekly)									
Financial Circumstances	Age of care-giver	Level of need/ care provided	Care relationship	Does CR have a right to a CCA? <sup>1</sup>	What eligibility criteria do they fit? (FACS)	Charge for care services	Would they be offered a Direct Payment?	Home care	Respite care				Telecare and Community Alarms	Meal services	Incontinence laundry services	Equipment and Aids	Transport
				Y/N	Critical Substantial Moderate Low	Self fund (£23,500+) Assessed (£14,450-23,500) No charge (under £14,450)	Y/N <sup>2</sup>		Type PC/M/D <sup>3</sup> Hours per day/wk	Short stay residential	Day care (DC)	Night sitting					
Lowest income/savings	Below Pension Age (25-60)	Constant 168 hrs	1	Y	C	Assessed charge + Set charge for respite 4 wks £106.30	Y PB <sup>4</sup> offered in all cases	4+ calls per day PC/M/D Am, lunch, tea, pm 30 mins 2 carers min.	PB Up to 4 weeks possibly more if carer stress (at home or care home)	Use PB to spot contract DC with res/ nursing home Self fund transport	Could use PB to fund night sits.	Number of hours based on assessed need Or consider day care	CA T if risk of falls, memory problem Refer to Falls team	Y 7 days a week lunch and tea Set charge	Home care can support with minor incidents or refer to Health Service	Y	different schemes in different localities CT Voluntary schemes
		Daily 35 hrs	2	Y	S	Assessed charge + Set charge for respite 4 wks £106.30	Y PB offered in all cases	PC/M/D Depends on carer Am, pm 30 mins	PB Up to 4 weeks (at home or care home)	Sign post via AgeUK (POP) or use PB to spot purchase 1 day DC	n/a	N/a they are safe to be left alone	CA T if risk of falls, memory problem Refer to Falls team	Y 7 days a week lunch and tea Set charge	n/a Home care can support with minor incidents	Y	different schemes in different localities CT Voluntary schemes

Care relationship type				Care-Receiver's Rights				Services provided to the care-receiver (weekly)									
Above pension age (65+)	Weekly 16 hrs	3	Possibly depends on situation	M	Not eligible Refer to FAB for benefits check	Not eligible	Not eligible Refer to Care navigator to self fund Or refer for floating support	Not eligible Would have to Self fund	Sign post via AgeUK (POP)	n/a	Not eligible Sign post via AgeUK (POP)	CA T if needed	Y 7 days a week lunch and tea Set charge	Not eligible	Y	different schemes in different localities CT Voluntary schemes	
	Constant 168 hrs	4	Y	C	Assessed charge + Set charge for respite 4 wks £106.30	Y PB offered in all cases *	4+ calls per day PC/M/D Am, lunch, tea, pm 30 mins 2 carers min.	PB Up to 4 weeks possibly more if carer stress (at home or care home)	Use PB to spot Contract DC with res/nursing home Self fund transport	Could use PB to fund night sits.	Number of hours based on assessed need Or consider day care	Y if risk of falls, memory problem Refer to Falls team	Y 7 days a week lunch and tea Set charge	Home care can support or refer to Health Service	Y	different schemes in different localities CT Voluntary schemes	
	Daily 35 hrs	5	Y	S	Assessed charge + Set charge for respite 4 wks £106.30	Y PB offered in all cases *(could not pay the care-giver in this situation as living together)	PC/M/D Depends on carer Am, pm 30 mins	PB Up to 4 weeks (at home or care home)	Sign post via AgeUK (POP) or use PB to spot purchase 1 day DC	n/a	Could consider if carer anxious or refer to befriending	CA T if risk of falls, memory problem Refer to Falls team	Y 7 days a week lunch and tea for both Set charge	n/a Home care can support with minor incidents	Y	different schemes in different localities CT Voluntary schemes	
	Weekly 16 hrs	6	Possibly depends on situation	M	Not eligible Refer to FAB for benefits check	Not eligible	Not eligible Refer to Care navigator to self fund Or refer for floating support	Not eligible Would have to Self fund	Sign post via AgeUK (POP)	n/a	Not eligible Sign post via AgeUK (POP)	CA T if needed	Y 7 days a week lunch and tea Set charge	Not eligible	Y	different schemes in different localities CT Voluntary schemes	



Care relationship type		Care-Receiver's Rights					Services provided to the care-receiver (weekly)										
Lower income/savings	Below Pension Age (25-60)	Constant 168 hrs	7	Y	C	Assessed charge + Set charge for respite 4 wks £106.30	Y PB offered in all cases *	4+ calls per day PC/M/D Am, lunch, tea, pm 30 mins 2 carers min.	PB Up to 4 weeks possibly more if carer stress (at home or care home)	Use PB to spot Contract DC with res/ nursing home Self fund transport	Could use PB to fund night sits.	Number of hours based on assessed need Or consider day care	Y if risk of falls, memory problem Refer to Falls team	Y 7 days a week lunch and tea Set charge	Home care can support or refer to Health Service	Y	different schemes in different localities CT Voluntary schemes
		Daily 35 hrs	8a	Y	S	Assessed charge + Set charge for respite 4 wks £106.30	Y PB offered in all cases	PC/M/D Depends on carer Am, pm 30 mins	PB Up to 4 weeks (at home or care home)	Sign post via AgeUK (POP) or use PB to spot purchase 1 day DC	n/a	N/a they are safe to be left alone	CA T if risk of falls, memory problem Refer to Falls team	Y 7 days a week lunch and tea Set charge	n/a Home care can support with minor incidents	Y	different schemes in different localities CT Voluntary schemes
		Daily 35 hrs	8b	Y	S	Assessed charge + Set charge for respite 4 wks £106.30	Y PB offered in all cases	PC/M/D Depends on carer Am, pm 30 mins	PB Up to 4 weeks (at home or care home)	Sign post via AgeUK (POP) or use PB to spot purchase 1 day DC	n/a	N/a they are safe to be left alone	CA T if risk of falls, memory problem Refer to Falls team	Y 7 days a week lunch and tea Set charge	n/a Home care can support with minor incidents	Y	different schemes in different localities CT Voluntary schemes
		Weekly 16 hrs	9	Possibly depends on situation	M	Not eligible Refer to FAB for benefits check	Not eligible	Not eligible Refer to Care navigator to self fund Or refer for floating support	Not eligible Would have to Self fund	Sign post via AgeUK (POP)	n/a	Not eligible Sign post via AgeUK (POP)	CA T if needed	Y 7 days a week lunch and tea Set charge	Not eligible	Y	different schemes in different localities CT Voluntary schemes

Care relationship type		Care-Receiver's Rights					Services provided to the care-receiver (weekly)									
Above pension age (65+)	Constant 168 hrs	10	Y	C	Assessed charge + Set charge for respite 4 wks £106.30	Y PB offered in all cases *(could not pay the care-giver in this situation as living together)	4+ calls per day PC/M/D Am, lunch, tea, pm 30 mins minimum 2 carers	PB Up to 4 weeks possibly more if carer stress (at home or care home)	Use PB to spot Contract DC with res/ nursing home Self fund transport	Could use PB to fund night sits.	Number of hours based on assessed need Or consider day care	Y if risk of falls, memory problem Refer to Falls team	Y 7 days a week lunch and tea Set charge	Home care can support or refer to Health Service	Y	different schemes in different localities CT Voluntary schemes
	Daily 35 hrs	11	Y	S	Assessed charge + Set charge for respite 4 wks £106.30	Y PB offered in all cases *	PC/M/D Depends on carer Am, pm 30 mins	PB Up to 4 weeks (at home or care home)	Sign post via AgeUK (POP) or use PB to spot purchase 1 day DC	n/a	Could consider if carer anxious or refer to befriending	CA T if risk of falls, memory problem Refer to Falls team	Y 7 days a week lunch and tea for both Set charge	n/a Home care can support with minor incidents	Y	different schemes in different localities CT Voluntary schemes
	Weekly 16 hrs	12	Possibly depends on situation	M	Not eligible Refer to FAB for benefits check	Not eligible	Not eligible Refer to Care navigator to self fund Or refer for floating support	Not eligible Would have to Self fund	Sign post via AgeUK (POP)	n/a	Not eligible Sign post via AgeUK (POP)	CA T if needed	Y 7 days a week lunch and tea Set charge	Not eligible	Y	different schemes in different localities CT Voluntary schemes

Source: Data from L2LAP1 and L2LAP2 (practitioners interviewed together).

<sup>1</sup> CCA: Community Care Assessment

<sup>2</sup> Normally Direct Payments cannot be used to employ the care-giver in situations marked with an \* because they are living with the care-receiver unless exceptional circumstances apply.

<sup>3</sup> P (Personal care), M (Meals), D (Domestic)

<sup>4</sup> PB (Personal Budget): used as the term for Direct Payments in LA2.

## Appendix 6: Care services matrix results for care-givers' entitlements in LA1

Care relationship type				Carer Rights and Recognition					Services provided to informal care-giver							
Financial Circumstances	Age of care-giver	Level of need/ care provided	Care relationship	Do they have a right to an assessment of need? What type of assessment would be offered?		What eligibility criteria do they fit? (FACS)	Charge for services	Would they be offered a Direct Payment Y/N (one off or ongoing)	Support services (note if funded via DP or LA)					Training	Info Advice Support	Leisure Services
				Carer Assessment (regular/substantial)	Assessed as part of Older Person's CCA	Critical Substantial Moderate Low	Rate: Max./Assessed/Flat		Carer Breaks (CB)	Domestic care services	Emergency care services (CRESS)	Equipment (e.g. furniture, white goods)	Transport support for carers			
				Type: CR <sup>1</sup>	Hours per wk	Hours/days per wk/year	Type		Type FBP RandR	Type/provider (CR <sup>1</sup> or AS) <sup>2</sup>	Type/provider	Type LC <sup>3</sup> DP <sup>4</sup>				
Lowest income/savings	Below Pension Age (25-60)	Constant 168 hrs	1	Y	Y if care receiver allocated to Community Care Team. If not encourage referral to CC team. Also refer to CHC <sup>5</sup>	Enhanced (E) or Standard (S) depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500 p.a. / Standard up to £250 p.a. depends on assessed outcome	If CHC NHS provide CB. Or if enhanced 70 hours p.a. via CR Or a direct payment £860	The carer probably could not use DP to cover costs of domestic tasks	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities Passport to Leisure discount
		Daily 35 hrs	2	Y	Y if care receiver allocated to Community Care Team. If not encourage referral to CC team.	Enhanced or Standard depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500 p.a. Standard up to £250 p.a. depends on assessed outcome	If enhanced 70 hours p.a. via CR Or a direct payment £860 p.a. If standard 35 hours p.a. or a DP of £430 p.a.	The carer should be able to use DP to cover costs of domestic tasks in carers own home	Refer to CRESS	Can use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities Passport to Leisure discount

		Weekly 16 hrs	3	Y	Care receiver may not be eligible for support	Likely to be Standard due to work issue	No charge	If standard up to £250 p.a. depends on assessed outcome	If standard 35 hours p.a. or a DP of £430 p.a.	The carer should be able to use DP to cover costs of domestic tasks in carers own home	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs  No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities  Passport to Leisure discount
Above pension age (65+)		Constant 168 hrs	4	Y	Y if care receiver allocated to Community Care Team If not encourage referral to CC team. Also refer to CHC	Enhanced or Standard depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500 Standard up to £250 depends on assessed outcome	If CHC NHS provide CB. Or if enhanced 70 hours p.a. via CR Or a direct payment of £860	The carer probably could not use DP to cover costs of domestic tasks	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs  No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities  Passport to Leisure discount
		Daily 35 hrs	5	Y	Y if care receiver allocated to Community Care Team If not encourage referral to CC team.	Enhanced or Standard depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500 Standard up to £250 depends on assessed outcome	If enhanced 70 hours p.a. via CR Or a direct payment of £860. If standard 35 hours p.a. or a DP of £430 p.a.	The carer probably could not use DP to cover costs of domestic tasks	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs  No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities  Passport to Leisure discount

		Weekly 16 hrs	6	Y	Care receiver may not be eligible for support	Could be enhanced, standard or basic depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500. Standard up to £250 depends on assessed outcome Basic no Direct Payment	If enhanced 70 hours p.a. via CR Or a direct payment of £860. If standard 35 hours p.a. or a DP of £430 p.a. Basic no Carer Break service	If enhanced / standard the carer should be able to use DP to cover costs of domestic tasks in carers own home	Refer to CRESS	If enhanced/ standard the carer can use DP to purchase equipment to help carer or cared for	If enhanced / standard the carer can use DP to cover transport costs No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	If enhanced/ standard the carer can use DP to pay for therapy sessions  Refer to organisations for advice and Carers Centre for emotional support	If enhanced/ standard the carer can use DP to pay for leisure activities Passport to Leisure discount
Lower income/savings	Below Pension Age (25-60)	Constant 168 hrs	7	Y	Y if care receiver allocated to Community Care Team If not encourage referral to CC team. Also refer to CHC	Enhanced or Standard depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500 Standard up to £250 depends on assessed outcome	If CHC NHS provide CB. Or if enhanced 70 hours p.a. via CR Or a direct payment of £860	The carer probably could not use DP to cover costs of domestic tasks	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs  No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities  Passport to Leisure discount
		Daily 35 hrs	8a	Y	Y if care receiver allocated to Community Care Team If not encourage referral to CC team.	More likely to be enhanced depending on how the carer was feeling about their work and caring role	No charge	Enhanced up to £500 p.a. depends on assessed outcome	If enhanced 70 hours p.a. via CR Or a direct payment of £860 p.a.	The carer should be able to use DP to cover costs of domestic tasks in carers own home	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs  No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities  Passport to Leisure discount

		Daily 35 hrs	<b>8b</b>	Y	Y if care receiver allocated to Community Care Team If not encourage referral to CC team.	Enhanced or Standard depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500 p.a. Standard up to £250 p.a. depends on assessed outcome	If enhanced 70 hours p.a. via CR Or a direct payment of £860. If standard 35 hours p.a. or a DP of £430 p.a.	The carer should be able to use DP to cover costs of domestic tasks in carers own home	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs  No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities  Passport to Leisure discount
		Weekly 16 hrs	<b>9</b>	Y	Care receiver may not be eligible for support	Could be enhanced depending on how the carer was feeling about their work and caring role or standard	No charge	Enhanced up to £500 p.a. Standard up to £250 p.a. depends on assessed outcome	If enhanced 70 hours p.a. via CR Or a direct payment of £860 p.a. If standard 35 hours p.a. or a DP of £430 p.a.	The carer should be able to use DP to cover costs of domestic tasks in carers own home	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs  No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities  Passport to Leisure discount
Above pension age (65+)	Constant 168 hrs	<b>10</b>	Y	Y if care receiver allocated to Community Care Team If not encourage referral to CC team. Also refer to CHC	Enhanced or Standard depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500 p.a. Standard up to £250 p.a. depends on assessed outcome	If CHC NHS provide CB. Or if enhanced 70 hours p.a. via CR Or a direct payment of £860	The carer probably could not use DP to cover costs of domestic tasks	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs  No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities  Passport to Leisure discount	

		Daily 35 hrs	<b>11</b>	Y	Y if care receiver allocated to Community Care Team If not encourage referral to CC team.	Enhanced or Standard depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500 p.a. Standard up to £250 p.a. depends on assessed outcome	If enhanced 70 hours p.a. via CR Or a direct payment of £860. If standard 35 hours p.a. or a DP of £430 p.a.	The carer probably could not use DP to cover costs of domestic tasks	Refer to CRESS	Use DP to purchase equipment to help carer or cared for	Use DP to cover transport costs  No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	Use DP to pay for therapy sessions Refer to organisations for advice and Carers Centre for emotional support	Use DP to pay for leisure activities  Passport to Leisure discount
		Weekly 16 hrs	<b>12</b>	Y	Care receiver may not be eligible for support	Could be enhanced, standard or basic depending on how the carer was feeling about their caring role	No charge	Enhanced up to £500 p.a. Standard up to £250 p.a. depends on assessed outcome Basic no Direct Payment	If enhanced 70 hours p.a. via CR Or a direct payment of £860 p.a. If standard 35 hours p.a. or a DP of £430 p.a. Basic no Carer Break service	If enhanced / standard the carer should be able to use DP to cover costs of domestic tasks in carers own home	Refer to CRESS	If enhanced/standard the carer can use DP to purchase equipment to help carer or cared for	If enhanced / standard the carer can use DP to cover transport costs No other transport discounts for carers	Refer to CR or AS for Manual Handling, VIP training Replacement care provided	If enhanced/standard the carer can use DP to pay for therapy sessions  Refer to organisations for advice and Carers Centre for emotional support	If enhanced/standard the carer can use DP to pay for leisure activities Passport to Leisure discount

Source: Data from L1LAM3

Notes:

<sup>1</sup> CR (Crossroads)

<sup>2</sup> AS (The Alzheimer's Society)

<sup>3</sup> LC Passport to Leisure card can be purchased by individuals in receipt of means-tested benefits or Carers Allowance at a cost of £6 per year and used to access leisure services in LA1.

<sup>4</sup> Use Direct Payment

<sup>5</sup> CHC (Continuing Health Care assessment via NHS)

## Appendix 7: Employment-related support matrix results for care-givers' entitlements in JCP1

Informal care-giver type				Employment-related support measures											
Financial circumstances	Age of care-giver	Level of need/ care provided	Care relationship	Employment Rights	Types of Care leaves		Flexible working	Support to re-enter employment in L1						Social Security Rights	
				Anti-discrimination protection in employment	Right to time off in an emergency		Right to request flexible working	JCP Obligatory Conditions (non compliance may result in sanctions)	Training Support		Financial Support to access employment			NI Contributions towards State Pension and other social security benefits	
					Un-paid	Paid			via either Work preparation support for lone parents, partners and carers (WPS) Or Work Programme		Flexible Support Fund (access and amount depends on Personal Advisor discretion)		Job Grant (valid up to 1.4.13)		
				Equality Act (2010)	Employment Relations Act (1999)		Work and Families Act (2006)		JCP training programmes	FEC <sup>1</sup> training courses	Interview costs Clothing (C) Transport (T)	Replacement care for Training (T) Interviews (I) Work (W)	One off payment during transition into work		NI Credits accessed via Carers Allowance (CA) Carers Credits (CC) JSA
Lowest income/savings	Below Pension Age (25-60)	Constant 168 hrs	<b>1</b>	Y (if applying for a job)	n/a	n/a	n/a	Signing on every 3 years No obligation to seek work	Y if available	Access any course Free with PL <sup>2</sup>	Y for T For C need proof of interview and savings	Yes for T and I W - No	Not eligible unless return to work 16+ hours per week	Eligible via CA	
		Daily 35 hrs	<b>2</b>	Y (if applying for a job)	n/a	n/a	n/a	Signing on every 3 years No obligation to seek work	Y if available	Access any course Free with PL	Y for T For C need proof of interview and savings	Yes for T and I W - No	Not eligible unless return to work 16+ hours per week	Eligible via CA	
		Weekly 16 hrs	<b>3</b>	Y (if applying for a job)	n/a	n/a	n/a	Signing on every 2 weeks Job Seekers Agreement Obligation to actively seek work	Y if available	Access any course Free with PL	Y for T For C need proof of interview and savings	Access depends on Personal Advisor discretion W - No	Y if coming off JSA £100 if single, no children	Eligible via JSA Not entitled to CA or CC	
	Above pension age (65+)	Constant 168 hrs	<b>4</b>												
		Daily 35 hrs	<b>5</b>												



		Weekly 16 hrs	6												
Lower income/ savings	Below Pension Age (25-60)	Constant 168 hrs	7	Y (if applying for a job)	n/a	n/a	n/a	Carer can choose to partake in JCP services	Can access WPS	Access any course Free with PL	n/a	Y for T and I W - No	n/a	Eligible via CA	
		Daily 35 hrs P-T work	8a	Y	Y	No right depends on employer policy	Y if worked for their employer for 26 weeks continuously	n/a	Not eligible because in work	Not eligible because in work	Not eligible because in work	Not eligible because in work	Not eligible because in work	Eligible via PT work If not can claim via CC Not entitled to CA	
		Daily 35 hrs	8b	Y (if applying for a job)	n/a	n/a	n/a	Carer can choose to partake in JCP services	Can access WPS	Access any course Free with PL	n/a	Y for T and I W - No	n/a	Eligible via CA	
		Weekly 16 hrs F-T work	9	Y	Y	No right depends on employer policy	Y if worked for their employer for 26 weeks continuously	n/a	Not eligible because in work	Not eligible because in work	Not eligible because in work	Not eligible because in work	Not eligible because in work	Eligible via FT work Not entitled to CA or CC	
	Above pension age (65+)	Constant 168 hrs	10												
		Daily 35 hrs	11												
		Weekly 16 hrs	12												

Source: Primary data collected from: L1JCP1, BDWPM2, L1LAM2, L1LAM3. Secondary data include: (HM Government, 1999, 2006c, 2010, 2011; Carers Direct, 2011ad,e,h,i, 2012a; Directgov, 2012n,o).

Notes:

<sup>1</sup> FEC: local further education colleges

<sup>2</sup> PL: Passport to Leisure scheme providing discounts to leisure activities and adult education classes

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