Exploring social inclusion and participation: assessing the impact of the Care Act (2014) on the social experience of being a carer

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A thesis submitted for the degree of Doctor of Philosophy

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Date of submission for examination (April 2022)

Acknowledgements

First and foremost, I want to thank my family: my husband Pete, my daughter Amber, and son Thomas. I want to thank you for your love, support, and encouragement all the way through my studies. This is your achievement as much as it is mine because none of this would be possible without your love.

I greatly appreciate the work and support of my supervisors, Professor Ewen Speed and Professor Susan McPherson, whose experience, knowledge, and sensitivity guided me through the last five years. Your insight and valuable feedback shall always be remembered.

To my wonderful friends: where would we be in life without good friends we can depend on in good times and bad. Sue and Rachael to name but two. Thank you for your truly wonderful friendship.

Finally, to my loving parents Chris and Noel: I hope you'll both be there in person when I get my floppy hat! I love you both dearly. Dad, thank you for proof reading my thesis; a true act of love that I will be forever grateful for!

Abstract

Summary:

The Care Act (2014) places a duty on Local Authorities to meet the eligible needs of carers in the form of personal budgets (PBs). PBs are positioned as a lever that will promote carer wellbeing. In the context of the Care Act wellbeing is conceptualised broadly to include economic and social participation. However, despite the 5.4 million adult carers in England, little is known about the efficacy of PBs on promoting carer wellbeing, particularly as PBs have been central to the personalisation agenda reforming adult social care in recent years. This thesis sought to explore this knowledge gap using a mixed-methods design built around three phases.

Methods:

Each phase is presented as a separate study as follows:

1. Examines the intentions behind PBs as a solution to the problem of caring: A post-structural policy analysis of Care Act (2014) guidance using: ‘What’s the Problem Represented to be?’ (WPR) method.
2. Identifies if the policy intentions led to improvements in carer wellbeing: A quantitative secondary descriptive analysis of national performance and inferential analysis of carer specific survey data.
3. Explores the lived effects of the policy intentions: A thematic analysis of interview data with 17 carers.

Findings:

The Care Act (2014) guidance reflects a ‘responsibilising’ agenda where care is viewed as the responsibility of the family. Regression analysis shows that PBs do not improve wellbeing and the number of carers assessed and supported between 2014 and 2020 has declined. The transactional mode of PB administration takes no account of the relational way in which care and care giving are experienced by participants.

Application:

This thesis demonstrates that further research is required to understand caring as both an ethical and political process that extends beyond the micro level interaction between people in families. Participation of carers in society cannot be achieved by a PB alone.

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List of Abbreviations

Terms used in this thesis (listed in chronological order)	Definition
PB	Personal Budget
TLAP	Think Local Act Personal
LA	Local Authority
NHSCCA (1990)	NHS and Community Care Act (1990)
WPR	What’s the Problem Represented to Be?
SALT	Short- and Long-Term Returns
CA	Carer’s Assessment
CASSR	Council with Adult Social Services Responsibility
SACE	Survey of Adult Carers in England
ASCOF	Adult Social Care Outcomes Framework
QoL	Quality of Life
ASCOT	Adult Social Care Outcomes Toolkit
PSSRU	Personal Social Services Research Unit
EoC	Ethics of Care
PoC	Politics of Care
ADASS	Association of Directors of Adult Social Services
CQC	Care Quality Commission
LGA	Local Government Association
ECLIPSE	Expectations, client group, location, impact, professionals, and service
STARLITE	Sampling strategy, types of study, approaches, range of years, limits, inclusions and exclusions, terms used and electronic searches
CASP	Critical Appraisal Skills Programme
BAME	Black, Asian, and Minority Ethnic
RCT	Randomised Controlled Trial
MPB	Managed personal budget
IMD	Indices of Multiple Deprivation
LTC	Long Term Condition
GHQ	General Health Questionnaire

Preface

"I simply do not see how…persons in the disabled persons situation seek to rely upon the rights afforded to them by article 8 (Human Rights Act – right to private and family life) without allowing that their carers have….corresponding rights which have to be brought into the equation. If article 8 protects the disabled persons physical and psychological integrity and it plainly does – then equally article 8 must protect their carers physical and psychological integrity".

R (A and B) v East Sussex CC (2003), Judge Munby

The above quotation is taken from a court ruling on the interpretation of the right to 'private life' contained under Article 8 of the Human Rights Act (1988) for adults with eligible social care and support needs under the Care Act (2014). The judge ruled that in the context of care arrangements for disabled people, their human right to dignity, independence, and participation in the community (as protected by Article 8) must be considered when public bodies assess risk and eligibility for support. Judge Munby observed that a balance must also be struck between the needs and rights of service users and the needs and rights of their carers. In that one does not take precedence over the other. The court case centred on the rights and needs of the disabled adult, and Judge Munby highlighted in this extract from his summing up that the needs and rights of family carers must not be ignored by public bodies.

It matters that public bodies consider the needs and rights of carers, because they have human rights to privacy and family life in the same way that all citizens do, including disabled adults. Human rights are human rights irrespective of whether a person has a caring responsibility, a disability, or lacks the mental capacity to make decisions for her/him/themselves.

Chapter 1 – Introduction

1.1 Background and context

This thesis assesses the extent to which personal budgets (PBs), and their framing as a policy solution to the problem of caring, under the Care Act (2014), can promote the wellbeing of people with caring responsibilities (referred to as carers in this thesis) in England.

The purpose of the assessment is to understand whether current English legal provisions are able to stand up to the policy promise that PBs can promote carer wellbeing. The Care Act (2014) defines wellbeing in relation to a series of social indicators including participation and inclusion in social and economic life. The Statutory Guidance in section 1.9 describes how a local authority can promote a person's wellbeing in ways that meet the person's needs and goals. Stating that *"the Act therefore signifies a shift from existing duties on local authorities to provide particular services, to the concept of 'meeting needs'"* (*The Care Act*, 2014).

In England, the Care Act (2014) was announced as a major reform of adult social care law (Whittington, 2016). The then Minister for Social Care, Norman Lamb, in a Department of Health press release, said it: *"was the most significant reform of care and support in more than 60 years"* (*Department of Health*, 2014). A forthright claim, it committed the government to transforming health and social care through personalisation and community-based support (Feldon, 2017; Whittington, 2016). Working alongside a national partnership of 50 organisations (including directors of adult and children's social care and third sector partners, for example, Age UK, Coalition for Personalised Care, and The Carers Trust), called Think Local Act Personal (TLAP); the Care Act (2014) cemented PBs as the method to achieve a personalised care and support system based upon the principle of promoting the individual wellbeing of people in need and their carers (*The Care Act*, 2014). TLAP described the Care Act as *"putting people in control of their care and support"* (2014).

Foremost in this move towards a more carer-centred focus was a recognition in The Care Act Statutory Guidance 2014, sections 9-13 (6.116), that: *“carers can be eligible for support in their own right…”*. Prior to the Act, carers had no legal right to access public funds in the form of a PB. Local Authorities (LAs) had the power to provide PBs to carers, but they were under no legal obligation to do so. Hence, take up was low, and many LAs had no established personalised systems to support carers (Mitchell *et al.,* 2017; Seddon, 2015; Whittington, 2016). All that changed when the Care Act (2014) was implemented in 2015, and carers were then entitled to a PB if they were assessed to have eligible needs.

1.1.1 Personal budgets

PBs are sums of money allocated to eligible carers. They can be administered in a number of ways. The most usual mode of administration is for the individual to receive cash in the form of a lump sum called a direct payment (DP). Alternatively, an eligible person may also ask the LA or third-party broker to manage the money on their behalf, which is known as a part DP. Choice in the way a PB is administered is seen as central to the new personalised system of support designed for carers in the Care Act (2014).

Although statutory rights to PBs for carers were new under the Care Act (2014), the idea of PBs as a method of administrating public funds to increase the choice and control of people who draw on social care support has been around for many decades.

Personalisation is a theory used to describe a person-centred system of care and support that puts the end user at the centre of controlling how their care needs are defined and met. Personalisation can also be thought of as a movement, that has its origins in the disability rights lobby (Slasberg and Beresford, 2016; Morris, 1999). This can be characterised as a grassroots movement of activist users of care and support services, who campaigned for an enabling society that viewed disabled people as people first with equal rights to a quality of life and place called home, enjoyed by non-disabled peoples (Slasberg and Beresford, 2016; Morris, 1999). Principles of self-directed support, including freedom from dependency from others for care whether that be family or state, underpin the user-centred movement.

The actions of activist service users led to the establishment of direct payments legislation in 1996. It enabled disabled people in England and Wales to have access to public money in order to purchase and manage their own care, therefore, increasing the choice and control they had over their lives (Slasberg and Beresford, 2016).

The association between DPs, choice, and control, was established with the Direct Payments Act (1996), and social policy in this field grew exponentially. Direct payments became known as PBs and they became synonymous with a language of empowerment and strengths-based approaches to care and support. They also became the central plank of government social care policy and a key mechanism by which disabled adults could enjoy better health and wellbeing, because they were directing their own care rather than having it imposed upon them by paternalistic public bodies (Needham, 2011; Ungerson, 1997).

In fact, Needham (2011), suggests: that PBs have the potential to reframe the relationship between the individual citizen and state by giving the individual more control and, therefore, more responsibility for the provision of their own care.

This transference of responsibility for the provision of care away from the state and onto the individual was to have significant consequences for family carers (Brostoff, 1989; Heaton, 1999). The establishment of the Direct Payments Act (1996) followed not long after the introduction of the NHS and Community Care Act (NHSCCA) (1990), which heralded a sea change in the approach to the provision of care and support. The NHSCCA (1990), shifted care away from long-stay institutions towards care being provided closer to peoples' homes in community settings that felt more like a home. One of the effects of this policy change was that more families were supporting family members and friends and, therefore, providing greater levels of care leading to reported increases in poorer health and wellbeing among the caring population, during the 1990s (Dalley, 1996; Twigg *et al.*, 1992; Twigg and Atkin, 1994) and 2000s (Barnes, 2006; Dalley, 1996; Howard and Child Poverty Action Group (Great Britain), 2001; Twigg *et al.*, 1992; Twigg and Atkin, 1994). There is a substantive literature reporting that carers are more likely to experience problems with their wellbeing and health compared to the non-caring population, (Borren *et al.*, 2014; Bucki *et al.*, 2016; Carmichael and Ercolani, 2016; Carers UK, 2014; Folbre and Nelson, 2000; Garlo *et al.*, 2010; Greenwood, 2016; Horner-Johnson *et al.*, 2015; Irfan *et al.*, 2017; Jessup *et al.*, 2015; Pivodic *et al.*, 2013; Roth *et al.*, 2009; Shahly *et al.*, 2013; Shilling *et al.*, 2016; Vasileiou *et al.*, 2017; Verbakel *et al.*, 2017). The effects of caring on health and wellbeing are discussed in detail in chapter three, section 3.5, which takes a detailed look at the impacts of caring on people's lives. The aim of this introductory chapter is to frame the discussion on the rationale for assessing the rhetoric surrounding the Care Act (2014) that PBs can promote carer wellbeing.

With limited support during the decade that followed the NHSCCA (1990), many carers reported increased strain and negative effects on their ability to have a life of their own alongside caring (Barnes, 2006; Dalley, 1996; Heaton, 1999; Howard and Child Poverty Action Group (Great Britain), 2001; Twigg *et al.*, 1990; Twigg *et al.*, 1992; Twigg and Atkin, 1994). PBs came to be seen and promoted as a way that carers themselves could enjoy better health and wellbeing, because they too (like disabled adults), would have a greater degree of choice and control over how they managed the balance between caring and their own lives (Dittrich, 2013; Jones *et al.*, 2014; Larkin and 2011; Moran *et al.*, 2011; Moule *et al.*, 2014; Woolham *et al.*, 2018).

In social policy terms, personalisation is synonymous with transformative public care systems, marking a move away from paternalism towards individual empowerment through choice and control over decision-making, and how needs are met. Debate in the literature argues that choice is established through market principles, where individuals are able to shop around and purchase services with their PBs (Clements, 2013; West, 2013). These market principles represent carers as consumers of services and products that may support them to balance caring with their own lives. Whilst Bartlett (2009) argues, more negatively, that personalisation has also come to mean an individualisation of care away from government responsibility, where PBs are effectively positioned as ‘window dressing’ to cover a political agenda of welfare state retrenchment (Bartlett, 2009). From this position, theories of personalisation have, therefore, become hijacked by a political-ideological programme, to privatise welfare through marketisation and cuts to funding for public services (Slasberg and Beresford, 2016; Whittington, 2016). The progression of this argument is that financial savings are seen as the real governmental agenda and not the empowerment of carers. If families provide care for free, then government does not have to. This creates the potential for significant savings for the public purse.

There is some evidence to support Bartlett’s thesis, when it was estimated in 2015 by a Carers UK report in conjunction with the Universities of Leeds and Sheffield, that carers saved the public purse, on average, £132 billion annually (Buckner, 2015). This figure was arrived at by taking the number of care hours reported by carers in their 2011 Census return and multiplying it by the average hourly cost of home care. The figure is, therefore, subject to the caveats of any estimate; however, what it did offer was an indication of the resource value that carers represented at that time point and brought to the attention of policy actors that unpaid carers were likely saving the public purse significant amounts of money.

Within this contested space, created by theories of personalisation, the idea that PBs will promote carer wellbeing takes on a particular significance. It becomes significant because, if PBs for carers is really a strategy for government to achieve its ideological aim of reducing the role of the state in the provision of welfare, as is proposed by Bartlett (2009), then it matters to scrutinise the claims surrounding the Act that counter this narrative and suggest the opposite. Exploring the policy intention behind PBs, as a solution to the problems that carers face, becomes a way of assessing that claim (phase one of this thesis).

It becomes important to understand whether the legal provisions contained within the Statutory Guidance of the Act for carers further either of these two competing discourses. Either PBs promote carer wellbeing, or they do not. If they do, this will substantiate the rhetoric surrounding the Care Act (2014), which suggests that PBs act as a lever in giving carers greater choice, whether that be purchasing power or inclusivity in, for example, being able to use their PB to be able to manage the balance between work and caring. (Dittrich, 2013; Jones *et al.*, 2014; Larkin, 2015; Larkin, 2011; Moran *et al.*, 2011; Moule *et al.*, 2014) If this is the case, then all things being equal it would be expected that the number of carers assessed and supported by PBs, since the introduction of the Care Act (2014), would have increased between 2014 and 2020, because assessment is the gateway to a PB. Carers must be found to have eligible needs as an outcome of assessment before they can receive a PB. It would also be anticipated that carers would report that their wellbeing had improved with the introduction of PBs, via the biennial carer survey, which is sent out to a representative sample of carers in each of the 152 English councils with adult social care responsibilities (CASSR), asking them how well they feel supported in their role and what would improve the quality of their lives (phase two of this thesis).

Or PBs do not promote wellbeing in the way that the rhetoric surrounding the Care Act (2014) suggest they do, because, as Bartlett (2009) claims, political ideology has corrupted the original aims of personalisation for its own ends to cut welfare cost and provision. Of course, Bartlett's claim cannot be assessed in isolation of other possible explanatory factors that might shed light on why PBs do not promote wellbeing in the way they were intended to if this is indeed a finding. This is the central question that this study seeks to resolve and examining the national evidence base in the form of carer- specific performance and survey data, offers a further way to assess the claims made by theories of personalisation. As well as examining the empirical evidence base about the efficacy of PBs on promoting carer wellbeing and exploring with a sample of carers what their experiences of PBs have been (phase three of this thesis).

The claim that PBs can promote wellbeing therefore deserves further critical scrutiny, and the next section outlines how this aim was achieved.

1.2 Aims and objectives

The purpose of this thesis was to assess the rhetoric surrounding the Care Act (2014) that PBs could promote carer wellbeing. This was achieved by designing the research around three phases. Each phase had its own research question which this thesis sought to address. Each phase ran concurrently alongside the others (also referred to as a synchronous design in the research methodological literature) (Creswell and Clark, 2007). These were:

- Phase one:- Examining the intentions behind PBs as a policy solution to the problem of caring – What were the intentions behind PBs as a solution to the problem of caring?
- Phase two:- Examining how the intentions were realised - Identifying if PBs impacted upon reported levels of subjective wellbeing across England – Did PBs promote carers' subjective wellbeing across England?

- Phase three:- Exploring what it is like to be on the receiving end of the policy intentions - Exploring insights from carers about the differences they felt PBs had made to their lives – What difference did PBs make to carers' lives?

Each phase is presented as an individual study within this thesis with its own methodology and findings sections. Findings from each phase were then merged during the discussion chapter to offer a synthesised assessment of the claim that PBs can promote wellbeing in the way that the Care Act (2014) intended.

This three-phased approach allowed me to do three things. Firstly, it enabled me to show comparison between what was intended with PBs, by scrutinising the language of the Care Act (2014) Statutory Guidance using a problem-questioning approach to policy analysis known as *'What's the Problem Represented to Be?'* (WPR) (Bacchi, 1999). Secondly, it assisted me to assess whether the policy intentions were realised in practice by examining the roll out of PBs across England. This was achieved by carrying out a quantitative secondary analysis of England-wide, carer-specific performance and survey data. Thirdly, I was able to explore what it was like to be on the receiving end of the policy intention, to be a carer with a PB. This was carried out by thematically analysing semi-structured interview data with 17 participants.

The remainder of this introductory chapter provides an overview and rationale for each of the three phases, such that readers can understand the basis for each analytical strategy chosen and how each phase was organised in this thesis.

1.3 Phase one: The policy intentions behind PBs – Why use a problem-questioning approach to policy analysis?

The first phase of this thesis examined the political commentary in the Care Act (2014) Statutory Guidance, by conducting a *'What's the Problem Represented to be?'* (WPR) analysis of the language presented in the guidance that what a carer's PB was intended to achieve.. The aim was to establish what the model of PBs described in the Statutory Guidance could achieve in practice. Was the Statutory Guidance framing PBs, as an empowering model that could facilitate carers' participation and inclusion in economic and social life, in the way that personalisation theory and the Department of Health press release implied?

1.3.1. Purpose and status of Care and Support Statutory Guidance

Different sources of law comprise the English legal system and social care law is made and passed by Parliament. These Acts of Parliament are supreme and are referred to as primary legislation. They are made up of a series of 'instruments' (Carr and Goosey, 2020). The law is hierarchical in structure and social care statutes, like the Care Act (2014) must be read down so as to be consistent with that Act's structure (Carry and Goosey, 2020).

Most Acts of Parliament contain only the essentials of the new law. The details of how a law should be implemented by a public body are done by issuing statutory instruments in the form of regulations and guidance.

Legally binding guidance (like the Statutory Guidance issued under the Care Act (2014)) to LA social care departments is issued under section 7(1) of the *Local Authority and Social Services Act (1970)*. This guidance has to be followed unless the public body gives a good reason for not doing so. Therefore where a public body is under a duty to do something under the Statutory Guidance, such as offer an assessment based on their being an appearance of need, generally it must do it. Whereas a power enables the public body to do something but does not compel it to do so (Carr and Goosey, 2020).

Legislation, regulations and guidance are subject to frequent modification and change because public bodies can be challenged in the High Court in judicial review proceedings (Carr and Goosey, 2020). Members of the public are owed what are referred to as public law duties under social care statute. These duties range from assessment, judgement making as to the significance and eligibility of need and care and support planning arrangements. Members of the public can challenge a public body if they believe it has not acted lawfully. Because legislation, regulations and guidance are subject to change through judicial review it is important to point out that all references to the Statutory Guidance in the thesis are as it was when the analysis of language was carried out in 2019.

1.3.2 What is a problem questioning approach to policy analysis?

Scrutiny of the language used in the Statutory Guidance applied a mode of policy analysis first developed by (Bacchi, 1999), called: '*What's the Problem Represented to be?*'(WPR). A post-structural Foucauldian-informed approach to policy analysis, it offered a discursive method for analysing the way in which policies construct problems in particular ways. The WPR approach gave me a set of analytical practices (in the form of a six-question model), that enabled me to question the way that caring was constructed as a social problem requiring a social policy response. This was achieved by questioning the assumptions and effects of constructing problems in particular ways, by asking, for example, what problem is being represented as something that PBs can solve for carers? The six-question analytical method considers the assumptions that lie behind specific policy solutions, which are referred to as problematizations. Bacchi's approach allows the questions to illustrate the presumptive nature of policy solutions, that give them intelligibility and explores the roots of problem representations by looking to history to see how objects such as caring are understood in the past.

Bacchi (1999) six-question model is shown below in table one. The questions are listed in chronological order in column one, and column two shows where each question was applied within this thesis. Readers will notice that the questions are not dealt with sequentially. This is a deliberate analytical choice because the thesis structure is built around the WPR questions. Bacchi refers to this as taking an *"integrated approach"* (Bacchi, 2009, p. 28). This meant that the aims of the thesis and design dictated how and when the questions were deployed. For example, the purpose of phase one was to examine the intentions behind using PBs as a policy solution to the problem of caring. However, before I examined what was intended, I needed to be clear about how the term carer first became part of policy discourse, and that required looking back in time to examine previous Statutes of Parliament to understand the meaning ascribed to people with caring responsibilities in the past. Therefore, question three 'How has this representation of the problem come about' was dealt with first in chapter four – a genealogy of caring before question two (which is dealt with in a later chapter). The next sections outlines the six-question model in more detail to show readers how the approach was applied in the thesis.

1.3.3 The role of WPR in the thesis

The WPR approach offers an analytical strategy for analysing governmental arrangements. With governmental understood in the expansive sense of the word (associated with Foucault) to incorporate a wide range of agencies and groups of professionals (Bacchi and Goodwin, 2016).

It provides the researcher with a way of thinking about policy analysis in a wider political context. As opposed to the more traditional forms of policy analysis that tend to view the policy making process as a problem solving one (Shaw, 2010). Traditional modes of policy analysis often take a linear, rationalist approach where the problem is assumed to be understood by all and therefore policy solutions can be agreed upon that will solve the problem. Thus, (in the context of this thesis), the problems that carers experience, such as challenges managing their own lives alongside caring responsibilities can be mitigated by access to public funds in the form of a PB.

In contrast Bacchi (1999) starts from the premise that policy solutions create rather than solve problems because solutions to problems reveal inherent assumptions about the nature of the problem and how it is constructed. Therefore, carer PBs as a policy solution to the problems that carers experience are problematic because they contain assumptions. The first assumption is that the term carer and the challenges they experience are self-evident and accepted as fact. Second, that PBs can mitigate the negative effects that caring can have on a person’s life, such as inability to maintain employment with caring or improve physical and emotional health and wellbeing.

How policy problems (the problem of caring) are defined becomes an important task for the analyst to explore; in order to show the role that politics plays in the policy making process (Bacchi, 1999).

This task is achieved by applying and answering the six-question model devised by Bacchi and each question is set out below for readers to be able to see how this mode of policy analysis was deployed throughout the thesis.

1.3.3.1 “What’s the problem represented to be in a specific policy?”

Identifying the ways in which the Statutory Guidance accompanying the Care Act (2014) defined the problem(s) of caring (problematisation) involved a discursive analysis of the language used to describe the caring population and the ways in which PBs were articulated as an entity that may remedy some of the challenges carers faced.

This analysis was carried out in phase one of the thesis (chapter five) which sought to address the intentions behind PBs as a solution to the problems that carers faced.

1.3.3.2 “What presuppositions or assumptions underlie this representation of the problem?”

The assumptions that underlie the way(s) in which carers are problematised follows on from question one. This question seeks to challenge the normative cultural values that inform the ways in which carers are framed in public discourse. This question was considered in phase one, chapter five where assumptions were discussed interchangeably alongside problem representations.

1.3.3.3 “How has this representation of the ‘problem’ come about?”

Going back in time to explore how carers were understood in earlier public discourses holds a mirror up to present day framings and understandings. It shows how carers experienced problems with their wellbeing and health long before PBs were identified as a policy solution. It enables the analyst to uncover how historical policy solutions were shaped by cultural, and societal social norms of their time.

This analysis occurred in chapter four – a genealogy of caring. Exploring when it was first possible to talk about the role of family in the provision of care and ways that people with caring responsibilities were problematised in the past opened up the possibility to compare these problematisation with current debates. It also indicated how the provision of care was an issue for societies long before it became viewed as something requiring a governmental response.

1.3.3.4 "What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?"

This question addressed the ways in which problem representations silence other ways of thinking and talking about the caring population and the causes of the challenges they face and experience. It opened up a way to think about alternative discourses for example, by comparing problem definitions from different cultural reference points.

This discursive analysis occurred in phase one, alongside questions one and two. It also drew from evidence presented in the conceptual review of key terms (chapter three) where contrasting theoretical debates about care illustrated how an ethics of care theoretical framework occupies a position of hegemony in debates about care and caring (Gilligan,1998).

1.3.3.5 "What effects are produced by this representation of the problem?"

In question five, Bacchi sought to establish how problem representations can have both positive and negative effects. Some effects may be intentional while others may be unintended. Who benefits from the problem representation and how?

This analysis occurred in two places in the thesis. The first place was in phase one where a discussion about the responsibilising effect of the problems of caring being framed at the individual level takes place. The second place is in the discussion chapter (eight). Here the findings from phase one were mixed with the findings from the qualitative interview data analysis. This showed how it was possible for carers to say what they did by indicating how what they said mirrored dominant framings of care giving. Question five also gave light to who may benefit from alternative problem representations and these were discussed in the discussion and conclusion of the thesis.

1.3.3.6 "How/where has this representation of the 'problem' been produced, disseminated and defended? How could it be questioned, disrupted or replaced?"

This final question is dealt with in the discussion chapter where findings from each phase of the thesis were drawn together to offer a synthesised answer to the research questions. It illustrated the role that power plays in the policy making process and how power can be used to reinforce dominant values for particular purposes (Bacchi and Goodwin, 2016).

Table 1. WPR Questions and chapter locations

WPR Question:	Chapter location:
1. What's the problem of caring represented to be in the Care Act (2014) guidance?	Chapter 5 – Phase one – Intentions of the Care Act (2014): A WPR analysis of the Guidance
2. What assumptions underlie this representation of the problem?	Chapter 5 – Phase one – Intentions of the Care Act (2014): A WPR analysis of the Guidance
3. How has this representation of the problem come about?	Chapter 4 – A Genealogy of Caring
4. What is left unproblematic in this problem representation? What are the silences? Can the problem be thought about differently?	Chapter 5 – Phase one – Intentions of the Care Act (2014): A WPR analysis of the Guidance
5. What effects (discursive, subjectification, lived) are produced by this representation of the problem?	Chapter 5 – Phase one – Intentions of the Care Act (2014): A WPR analysis of the Guidance Chapter 8 - Discussion
6. How can this representation be disrupted or replaced?	Chapter 8 – Discussion

1.4. Phase two: Were the policy intentions realised?

The second phase moved on from phase one to examine if the policy intentions were realised in practice. As discussed earlier in this chapter, if the intentions of PBs were to promote the wellbeing of carers, by increasing the choice and control they could exercise over their own lives, then it would be anticipated that the number of carers receiving assessments of need and PBs would have increased since the implementation of the Care Act in 2015. It would also be anticipated that carers would report improvements to their subjective wellbeing, as a result of receiving a PB and/or report that they have a greater degree of choice and control over managing the balance between caring and their own lives. This phase of the thesis was achieved by a quantitative examination of the picture across England to assess the claim that PBs can promote carer wellbeing. Each quantitative data set is outlined for readers on the next page. But before that outline it is necessary first for readers to understand the ways in which a PB can be taken by carers.

There are four ways in which a PB can be administered (*The Care Act*, 2014).

1. Direct payment (DP) only – Where the carer has made an informed decision that they want to be responsible for purchasing services for themselves under direct contracts with providers, to which they will be the formal party. DPs are often the preferred method of administration for LAs because the responsibility is placed on the individual carer to manage the administrative and contractual obligations of the budget.
2. Part DP – Where the carer decides to take some of the PB allocation as DP and some as a managed PB (where the LA arranges and manages the service between the carer and provider, for example a home-care service).
3. Managed PBs – At the carer's request, the LA either directly provides services to the value of the PB or places the budget with a third party/provider under a contract (for example, brokers who manage payroll and recruitment of personal assistants). Under this latter kind of arrangement, the contract is between the council and the third party/provider, whilst the day-to-day arrangements are between the carer and the third party/provider, as provided for in the contract.

4. Commissioned support only – The LA is the sole contractor with the provider of support to the carer. The carer plays no role in the management of this relationship. For example, the LA contracting with a sitting service provider to give the carer a break from their role. This type of support reflects the traditional model of social work, where a care package is arranged on behalf of the individual or family and the family has no say in who provides that care (Disability Rights UK, 2020).

The impact of PBs was measured in this phase of the thesis using carer-specific elements of social care England-wide performance and survey data. Performance data were used to describe frequencies and measures of central tendency of the number of carers assessed and supported since the introduction of the Care Act in 2014, and up to and including data for 2020 (data for 2021 onwards were not publicly available when the analysis was carried out). This was achieved using short- and longer-term activity returns (SALT) data, which captured the number of carers who had had a carers assessment (CA), and the number of carers receiving different types of support (outlined in one of four ways above).

CAs are a gateway to a PB. The outcome of an assessment determines eligibility for support. These were new performance data that LAs were expected to capture from 2014/15 (from the introduction of the Care Act (2014)). They recorded the numbers and types of support being offered to carers by Councils with Adult Social Services Responsibility (CASSRs). These data would show whether the number of carers assessed had increased, alongside the number receiving PBs. Changes to the way that data were collected about CAs, and support from 2014, meant that it was not possible to carry out a pre- and post-Care Act measure of impact. The data were incomparable (NHS Digital, 2014 - 2020).

Regression analysis was used to test the hypothesis that PBs promote carer-subjective wellbeing, using data from the 2018/19 biennial cross-sectional survey of carers in England.

The statistical test used was a test of association between not having, and having, a PB, and seeing what effect this had on wellbeing as an outcome variable. The survey of Adult Carers in England (SACE) is sent out to a representative random sample of carers known to each CASSR who have either received a CA or review of their circumstances in the preceding year. It uses a mix of scaling and open questions to explore what matters most to carers, how they achieve a balance between caring and having a life of their own, and what would make life better for them. In order to test the hypothesis, that PBs can promote carers' wellbeing, a wellbeing-outcome variable was constructed using questions from the SACE that aligned with indicators of wellbeing, as defined by the Care Act (2014), in order to determine whether PBs were associated with improve wellbeing scores.

The regression analysis was complimented with data from the Adult Social Care Outcomes Framework (ASCOF). The carer-specific elements of this survey data were developed to learn more about whether services received by carers helped them in their caring role, and their own perceptions of how well services to the person they cared for supported them in their role. Three outcome measures were chosen for analysis, because they indicated whether services received by carers helped them in their caring role, they were: 1) Quality of life (QoL), measured using a validated scale; 2) satisfaction with social services; and 3) involvement in discussions and decisions about the cared for. The remaining outcome measures were not chosen because they related specifically to the adult requiring care and support and were excluded from this enquiry.

1.5 Phase three: The lived effects of the policy intentions

The third phase of this thesis sought to provide a narrative and context behind the quantitative findings from phase two. Phase two analysis would not be able to explain what it felt like to receive a PB. This final phase carried out a qualitative thematic analysis of 17 semi-structured interviews, with carers, to understand the difference that PBs made to their lives. The aim of this phase was to understand if PBs were having any materially positive impact upon carers' lives, from their perception. Were interviewees, for example, able to balance work with caring as a result of receiving a PB? Were they able to maintain relationships/friendships? (Two of the Care Act (2014) wellbeing indicators). Did they feel that PBs gave them a sense of choice and control over how they managed the balance between caring and having a life of their own?

The geographical area under investigation for this final phase was England because the Care Act (2014) is an England-only adult social care statute. The thesis spanned a six-year time period (2014 to 2020). It began with the enactment of the Act in 2014 and looked at empirical research on the impact of PB on carer wellbeing, up to and including 2020. The population being studied was adults with caring responsibilities looking after adults only The rights of carers of people under the age of 18 and young carers' needs are primarily addressed under a separate Act – the Children Act (1989) (as amended by the Children and Families Act 2014) – and therefore were excluded from this thesis.

Now that readers have a clear sense of what this thesis intended to achieve, and how; the next chapter moves on to explain why a mixed-methods design was chosen. The reason for offering this methodological discussion now is because each phase and its corresponding question is treated as a separate study, complete with its own methods and findings section. Therefore, it would not make analytical sense to have this discussion in any of the other methods sections.

Chapter 2 - Rationale for using a mixed-methods design

2.1 Introduction

In the previous chapter, a background and context were provided arguing the need for a study of this kind. It demonstrated a purpose behind assessing the claim made by the Care Act (2014), that PBs can promote carer wellbeing, because theories of personalisation contest whether or not PBs can, and are, being used in the way they were intended to empower carers to be able to balance their own lives alongside a caring responsibility.

The introductory chapter also offered a rationale for the structural approach taken which separated each research question into an individual research phase. However, no theoretical rationale was presented for this approach. This chapter now gives readers a methodological and theoretical rationale for adopting a three-phased – mixed-methods design, applying a complementary model created by Cairney (2013), and a design typology for mixed-methods studies, developed by Schoonenboom and Johnson (2017).

Each of the Schoonenboom and Johnson (2017) seven dimensions are set out in turn for readers to illustrate how this thesis demonstrated a rigours and replicable approach to design thinking and choices made. The complementary model, offered by Cairney (2013), provided the structural approach needed for this thesis, where ontologically-competing research designs are used to address each of the three research questions.

2.2 Mixed-methods design typology

A mixed-methods design has seven dimensions that need to be accounted for in the design process (Schoonenboom and Johnson, 2017). These are: *"Purpose, theoretical drive, timing, point of integration, typology, typological versus interactive approach to design or planned versus emergent design and design complexity"* (Schoonenboom and Johnson, 2017, p. 1).

Each design characteristic is taken in turn, now, to provide readers with a sound rationale for the use of mixed methods, to assess the impact of PBs on promoting carer wellbeing.

2.2.1 Purpose of mixing methods

According to Schoonenboom and Johnson (2017), the purpose of combining quantitative and qualitative research methods is ultimately to strengthen a study's conclusions and to be able to answer a study's research questions. A popular classification of research purposes was developed by (Greene *et al.*, 1989). Two classifications (of the five) Greene and colleagues developed were adopted by this thesis, these were: *Initiation* and *Expansion.* The three remaining classifications were not appropriate in the context of this thesis, because they refer to what are termed as sequential designs. These are where the findings from one method are required to inform the design of another. In this thesis, each phase ran concurrently alongside the other (also referred to as a synchronous design in the research methodology literature) (Creswell and Clark, 2007).

Initiation (as a purpose of mixing) aims to explore new perspectives and the discovery of contradictory positions that may result from analyses adopting different theoretical positions. This was of particular interest. Being able to assess claims made by the Care Act (2014), that PBs can promote carer wellbeing using different lenses through which to assess that claim, offered a more nuanced and complete answer to the research questions and analysis of the contested space occupied by PBs, and theories of personalisation. While *expansion,* as a rationale for mixing, aimed to broaden the depth of this enquiry by using different methods through which to view the research topic being studied.

These classifications of purpose can be seen in the way that this thesis was designed to explore and assess the claim made by the Care Act (2014), that PBs could promote carer wellbeing. The assessment of the claim was investigated from three different perspectives: 1) Understanding the intention behind PBs as a policy solution to the problem of caring; 2) Identifying if PBs improved subjective wellbeing scores; 3) Exploring insights from carers about the difference PBs made to their lives.

Assessment of the policy intention behind PBs was undertaken using a post-structural approach to policy analysis, called WPR. This first phase was designed to question the assumptive nature of PBs as a policy solution to the problem of caring. Bacchi (1999), discursive model provided the problem-questioning approach needed that was not offered by other more traditional modes of policy analysis, that tended to view the policy-making process as a problem-solving, rather than a problem-creating, one (Shaw, 2010). The methodological approach to phase one is dealt with in chapter five: *'Intentions of the Care Act (2014): A WPR Analysis of the Guidance'.*

Of central interest in phase two, was to demonstrate measurable changes in subjective wellbeing scores, in order to test the theory presented in the guidance that PBs can promote carer wellbeing. This lent itself well to the use of quantitative methods and regression-based modelling, to identify if a statistically significant association existed between not having a PB and having a PB, and the effect of this association on wellbeing as an outcome variable. Linear regression analysis provided strength in determining associations between the measured variables, and were chosen on that basis (Field, 2013).

The statistical analyses would not be able to explain how it felt to receive a PB, nor provide the perspective from carers themselves on the extent to which PBs promoted their wellbeing, and participation, in economic and social life. Therefore, interviews were carried out in phase three, to enrich the enquiry by exploring subjective accounts from 17 carers about their experiences of receiving a carer's PB, from one LA in the East of England region.

The use of both quantitative and qualitative methods offered what Bryman (2016, p. 6) refers to as a "*diversity of views"* as a rationale for mixing *"uncovering relationships between variables through quantitative research while also revealing meanings among research participants through qualitative research*" (Bryman, 2016). Bryman reclassified Greene's original classification of research purposes to include diversity of views and *"utility"* (p.6). Utility means finding and applying the most effective method that addresses the research questions. The methods chosen for this thesis were sourced on the basis of their utility in answering each of the questions posed.

2.2.2 Theoretical drive

The second of Schoonenboom and Johnson (2017) seven dimensions (listed in 2.2 above), that need to be accounted for in the design process, is the study's theoretical drive. This refers to the ontological and epistemological positioning about the nature of knowledge and how it can be captured (Morse, 2009).

The major theoretical challenge this thesis faced, was how the tension of mixing opposing ontological questions about the nature of reality and approaches to the acquisition of knowledge could be resolved. Chiefly, that positivist and interpretivist paradigms were regarded as incompatible (Lincoln and Guba, 1985).

Using a mixed-methods design involved adopting data collection and analyses methods that fundamentally disavowed each other, because they had opposing views about the nature of reality and how it could be observed and captured. Positivism rests on the assumption that reality is something that can be observed, external of human thought and interaction (Clark, 1998; Sousa, 2010). Therefore, data and their analyses reflect an objective truth about what is seen and understood. Whereas, interpretivism starts from the basis that reality is socially constructed through social processes, therefore, there is no such thing as objective reality or singular truth to explain phenomenon (Burr, 1995).

Post-structuralism, as a theoretical approach which informs the WPR method of policy analysis applied in phase one, stands outside of any notions of truth, and therefore, rejects the tenets of positivism associated with some quantitative and qualitative methods (Bacchi, 2016). WPR challenges the view of a 'sovereign self', and, therefore, analysis of interview data as a representation of an authentic self is not possible, because the way in which interviewees position themselves is of itself a social practice (Bacchi and Bonham, 2014). Therefore, the use of thematic analysis to represent real accounts of carers cannot be 'real' because there are no such bounds within a post-structural, social constructionist view of the world, where what is said reflects a neutral account of knowledge. Thematic analysis finds its origins within a critical realist paradigm, which positions the accounts of interviewees as representing a 'real' self (Braun and Clarke, 2014).

Similarly, the notion that secondary analysis of performance and survey data can present real evidence of the impact of PBs on carer wellbeing, as phase two of the thesis suggests, by using a regression-modelling strategy, is disavowed from a post-structural perspective.

Although research designs are traditionally framed as a dichotomous choice between quantitative (positivist) and qualitative (interpretivist) approaches, this is challenged by some Creswell and Clark (2007); Hanson (2005), as a false choice. Creswell and Clark (2007) argue it is possible to carry out mixed-methods research that does not relegate the qualitative as secondary to the quantitative elements, as is often the case in their view. These pragmatic stances advocate a 'third way' of combining both, such that the research question dictates the best method, referred to as mixed methods (Denscombe, 1998; Dyson and Brown, 2006).

Pragmatism was the paradigmatic approach adopted by this thesis. It provided the rationale for both quantitative and qualitative modes of research enabling evidence to be mixed and knowledge increased in a meaningful way that may not always be produced by using one method alone (Creswell and Clark, 2007).

Pragmatism gives primacy to the research questions over debates about hierarchies of knowledge and truth, and is considered its own paradigm (Tashakkori and Teddlie, 2010). It shifts thinking away from questions about what constitutes valid knowledge, towards a consensus approach that accepts a multiplicity of methods have value in describing and understanding the social world, and in the case of this thesis, the impact of PBs on promoting carer wellbeing. Morgan (2007) describes this approach as moving researchers towards an identity as 'communities of practice', where an emphasis is placed on the benefits of interdisciplinary knowledge towards an understanding of the social world and social problems (Morgan, 2007). Cairney (2013, p. 6) goes further, and suggests that mixing methods encourages *"methodological sophistication"*, because researchers are able to draw from a range of explanatory frameworks, each offering a differing perspective on the research topic. This he suggests promotes interdisciplinary collaboration, and thus, in the words of Ostrom in Cairney (2013), supports researchers to *"overcome our own heterogeneities so as to achieve a better understanding of the world around us"* (Cairney, 2013, p. 5).

The assumption, behind a pragmatic philosophical approach, is that quantitative and qualitative methods, alone provide only a partial picture of the phenomena of the impact of PBs on promoting carer wellbeing. Or one lens through which to answer a research question. This point is picked up and elaborated on further by Cairney (2013) who discusses how the use of multiple theories to inform research is particularly useful in policy-based studies, because of the multiple disciplinary perspectives that inform the policy making process, and those involved in policy making arenas.

It is important to stress that although pragmatism is considered a philosophical approach to research in its own right, some commentators (Dyson and Brown, 2006) express caution on blurring the boundaries between what they see as separate philosophical positions about the nature of reality, that cannot be mixed, because it is not possible to hold more than one philosophical belief as the ‘true’ position, at the same time. From this position, the mixing of methods is both ineffective and untenable. It is a contested research philosophy; but this thesis argues in favour of pragmatism, because the assumption underpinning this thesis is: that the notion of an externally-observable objective reality is of itself a social construct (Burr, 1995).

On that basis, it is justifiable to collect and analyse both quantitative and qualitative data that offer a further lens through which I can assess the claim that PBs will promote carer wellbeing. Social constructionism does not deny the existence of a material world, rather how that world must be understood in relation to its historical, cultural, and political context (Burr, 1995).

2.2.3 Timing

Timing is the third dimension to account for in the research design process. This related to the way in which elements of the research design were managed and executed. Timing, in the context of this thesis, was described as concurrent (also referred to as synchronous in the literature). This meant that each phase of the research ran parallel with the other phases. Neither phase was required to be carried out before another could begin. The way in which the studies are presented does not reflect the timing or order in which they were carried out. In fact, each phase was developed simultaneously, unlike sequentially timed projects, where the findings from one phase of a study are required in order to design the next phase.

2.2.4 Point of integration

The fourth dimension important, when designing mixed methods studies, is the point at which the different collection and analyses methods are mixed together. If they are not, then the thesis cannot claim a mixed-methodological design.

A way to present multi-theoretical perspectives is offered by Cairney (2013), which is referred to as a complementary model. This approach treats each theoretical perspective as a separate study, complete with its own methods and findings section, and this is the model of presentation adopted by this thesis. The point of integration, applying Cairney's model, occurs in the discussion phase where findings are drawn together and synthesised. How this synthesis was achieved is discussed next.

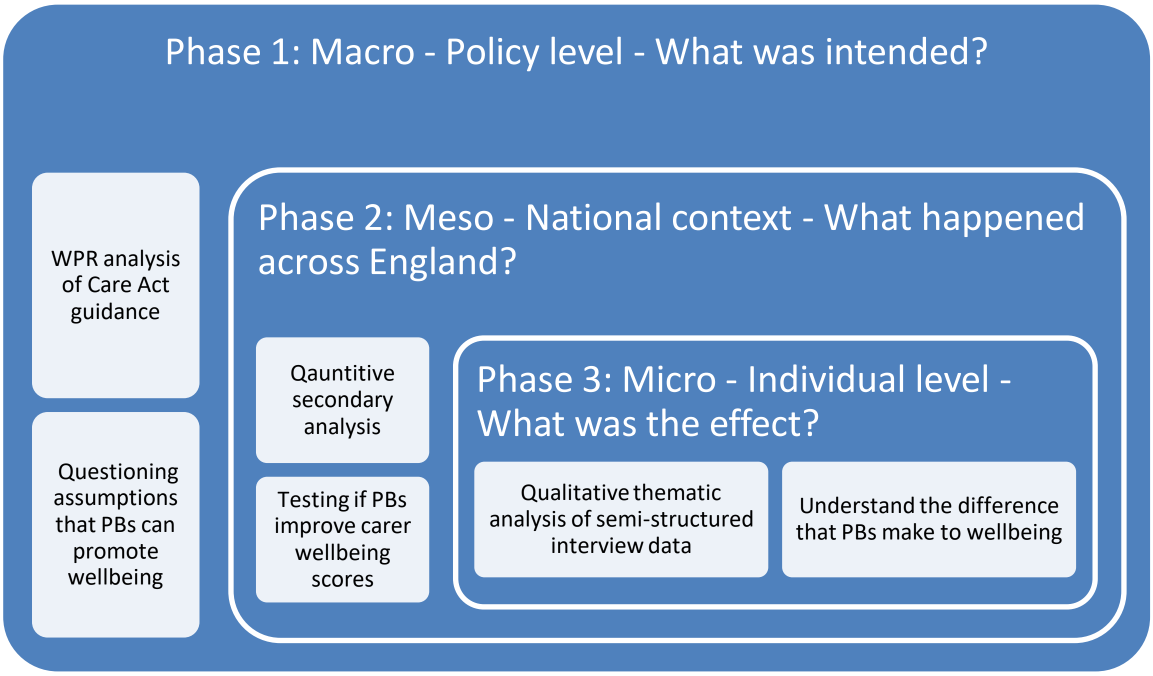
The use of multiple lenses opens up a space in the discussion chapter to discuss the assumptive natures that underpin each of theoretical perspectives applied in the design of the thesis. It enabled the synthesis of findings form a WPR (discursive) analysis of the Care Act (2014) guidance, with those of the linear regression modelling to show how policy and outcomes from policy decisions can be understood as a social practice as well as a statistical finding. The use of WPR as an analytical framework brought out into the open the different realities and their effects on interviewees shaped by the guidance accompanying the Care Act (2014). Such that, findings from a thematic analysis of interview data could be synthesised with findings from the WPR analysis of the guidance, to show, not just what interviewees said, but how it was possible for participants to say what they did during interviews, and how that related to the dominant framings of caring presented within the Care Act (2014) guidance, and in the empirical literature.

2.2.5 Typology of design

The fifth classification to consider in the design process was the typology of design chosen. The type of design used in this thesis is described as synchronous. A synchronous design is one where the different data collection methods run concurrently, as opposed to sequentially. For example, the quantitative secondary data analysis was not a precursor of the qualitative interviews. One was not the product of the other. The flow of quantitative and qualitative ideas are presented in the concept map in Figure one on the next page, modified from Creswell and Clark (2007).

A synchronous model is specifically used for research designs where the researcher intends to merge findings from the analyses during the discussion phase. The emphasis here is on viewing the discussion as a whole system; mixing the findings together to show how each of the study's results can be blended to offer a multi-lens perspective in answering each of the research questions.

Figure 1 Concept map - mixed methods synchronous design



Source: Creswell and Clark (2007) Designing and Conducting Mixed Methods Research

Figure one above shows a visual depiction of a synchronous design where no method takes priority or precedence over another, either in knowledge hierarchy or timing, and is often labelled in research notation form as: QUAL+QUAN (Morse, 2009).

2.2.6 Typological versus interactive approaches to design

The sixth classification to account for in the design process refers to the distinction made between design as a product and design as a process (Schoonenboom and Johnson, 2017). Typological versus interactive refers to the extent to which the research design was created from the start (produced as a mould in which the enquiry can be fit), versus an interactive approach to design which emerges over time as thinking shifts the design parameters. This latter category is referred to as a dynamic approach to design by Creswell and Clark (2007). This thesis took a dynamic approach to design rather than a product approach. Although the rationale for using mixed methods was made early on, no decision was made from the outset about the analyses methods to be used for each of the three phases. These emerged over time as, for example, I examined the policy analytical literature to identify an approach that offered a problem-questioning method.

Dynamic approaches like this *“view design as a process, in which a certain design as a product might be the outcome of the process, but not its input.”* (Schoonenboom and Johnson, 2017, p. 121). The aim of the researcher, where a dynamic approach is taken, is to produce an end product in which the design features (listed above) fit seamlessly together. During the research, it is up to the researcher to ensure that components of the research still fit the original design. If not, then the researcher must restore the fit between them in order to deliver a final product that can demonstrate the five key features of design. For instance, the research questions that corresponded with each of the three phases directed and informed the theoretical approach taken to the analysis

2.2.7 Dimension of complexity

The final dimension of Schoonenboom and Johnson (2017) is accounting for the level of complexity in the design process. Complexity is divided in the literature in relation to two dimensions. These are referred to as studies that are either simple or complex designs (Guest, 2013).

This thesis is presented as a complex design because of the multi-level data being analysed at macro, meso and micro levels (as illustrated in Figure one above). Complexity can also be thought about where a study adopts different ontological positions involving multiple levels of reality, which this thesis does. Integration of the data collected in this thesis is not simply about integrating the findings from quantitative and qualitative methods of collection and analysis, but also the integration of data originating from different sources and at different levels. For instance, government guidance is different data to LA performance and survey (numerical) secondary data. Which in turn differs from the primary data collected via interviews with carers.

Now that a clear rationale has been presented for applying a mixed methods design in order to address the research questions, the next chapter moves on to operationalise key terms and concepts used in this thesis. This begins with an exploration of how concepts are understood in the literature, and how these empirical understandings were used to inform the working definitions applied. The key conceptual terms that required definition were care, carer, need, and wellbeing. The next section begins with care at a conceptual level because care is the activity that is performed by people with caring responsibilities who have become defined by the category of carer.

Wellbeing is operationalised separately in Chapter five, section 5.8 where phase one of the thesis carries out a WPR analysis of the Care Act (2014) guidance, and a WPR conceptual analysis of wellbeing.

The reason for separating the operationalisation of wellbeing from other key concepts is two-fold. Firstly, wellbeing is the central concept and a key part of the overarching question that frames this thesis. The duty to promote wellbeing runs through the entirety of part one of the Care Act (2014) care and support guidance. It is central to a LAs duties in relation to assessment and support of carers. Secondly, an analytical decision was taken to apply Bacchi's WPR analysis to wellbeing, as a construct on the basis this would offer a more detailed analysis and understanding of how wellbeing has become understood and used in policy discourses like the Care Act (2014) accompanying guidance.

2.3 Positionality

The motivation for carrying out this research was two-fold. Professional and personal experiences of caring were a catalyst for wanting to explore to what extent PBs could improve carers' lives. As a qualified social worker since 1998, I held responsibility for the roll out of PBs for carers in two different LAs between 2010 and 2015. I observed first hand how my employer had some flexibility in how they interpreted the Statutory Guidance because there was significant variation in how each LA I worked for delivered PBs to carers.

In one authority the budget for carers' PBs was much more generous and personalised compared to the other. Despite these differences, the amount of public money we were able to allocate to eligible carers (from my experiences) did not support eligible carers to be able to for example, maintain or obtain work alongside caring. I was acutely aware that we relied heavily on the good will of families in the provision of care for adults with care and support needs. Without their support the LA would otherwise have to pay for the cost of care for adults with eligible care and support needs. It was my personal belief (anecdotal) that PBs were a tacit way of locking carers into that role.

Then, like many people, life events took over and I found myself in a caring role for three years, looking after two relatives who were diagnosed with terminal cancer within three months of each other. I was on the receiving end of, what felt like at many times, a broken system. Paid carers occasionally not turning up when expected and carers' assessments being used as a gate keeping function for scarce respite beds where one had to prove ones' need for a break. In other words, why you were not able to care. It felt very much like a deficits model of support when the rhetoric surrounding the Care Act (2014) and theories of personalisation described how assessments should take a strengths-based approach. Identifying what was working well in a caring role, rather than what was not.

I felt there was a dissonance between the policy rhetoric and the practice and personal reality. Yet I was also aware that my professional and personal experiences of caring were one perspective. I wanted to explore and understand how PBs were being rolled out and experienced by carers in England. I wanted to examine and understand if they were leading to any materially positive benefits for carers and identify if there was empirical evidence to back up my own experiences.

2.4 Summary

This chapter offered a rationale for taking a multi-theoretical perspective to address the research questions in strengthening the conclusions drawn by this thesis and being able to draw from a range of explanatory frameworks in order to offer a nuanced assessment of whether or not PBs for can promote carer wellbeing in the way that the Care Act (2014) intended.

Chapter 3 – Conceptual review of key concepts

3.1 Introduction

The previous chapter offered a robust analytical rationale for adopting a mixed methods design to address the research questions. To be able to carry out an assessment of the extent to which PBs can promote the wellbeing of carers, we first must operationalise what is meant by these conceptual terms.

The intentions behind PBs as a policy solution to the problem associated with caring rely upon a particular understanding of what is meant by concepts such as care, caring, need, and wellbeing. It is the meaning that the Care Act (2014) gives to these terms that gives them intelligibility and determines who gets access to a carer's PB, and who does not. For example, how a carer's needs are defined determines their eligibility for a PB. This is because eligibility for a PB turns on there being a significant impact upon a carer's wellbeing (The Care and Support (Eligibility Criteria) Regulations, 2015)).

Consequently, it matters to critically assess the meaning that the Care Act (2014) guidance relies on when it defines whose needs meet the eligibility criteria, and whose do not, because that meaning gives terms like carer and wellbeing intelligibility. Intelligibility, in turn, produces knowledge and that knowledge informs practices. These practices determine who receives a carer's assessment, who is eligible for PB, and who is not. Bacchi (1999) refers to this as governing practice.

Comparing how the Care Act (2014) guidance defines and applies these concepts with that of the empirical literature, opens up a space to identify any contestations with their usages. It facilitates and foregrounds phase one of the thesis in critically examining the intentions behind PBs as a policy solution to the problem of caring.

3.2 What is care?

There are two key theoretical positions offered in the literature that describe and explain what care is. They are ethical and political theories of care and both present the object of their study differently (Conradi, 2020). An ethics of care (EoC) theoretical perspective frames care as a loving, dutiful act between people. An EoC perspective is concerned with questions of why empathy, love, attachment, and reciprocity in care giving are undervalued and under studied constructs in academia and society more broadly (Gilligan, 1993; Noddings, 1992). Whereas, a political theory of care (PoC) frames care in relation to its function to society – what purpose it serves, and considers questions such as how we come to care; and how does care become socially constructed as a dutiful, loving act? (Tronto, 1993).

EoC explanations of what care is focus on the micro-level relationship between givers and receivers of care, with a focus on the reciprocity that exists between the care giver and receiver of care. Conversely, PoC explanations look to the macro environment and consider how the act of care can be considered discriminatory and oppressive, because it is largely seen as a female-orientated task. Therefore, care can be viewed as one of the sites of women’s oppression by society (Gilligan, 1993; Tronto, 1993; Ungerson, 1997).

In English-speaking countries, the concept of care has meaning in several forms, and they form part of a lexicon and discourse in health and social care study and practice (Langier, 2016). Across the western world, cultural norms exist around care that do not exist in other cultures. The meaning ascribed to care in the English-speaking world shows the important role that language plays in the production of knowledge.

Discourses of caring can, therefore, be thought of as having a cultural component. For example, in South Asian cultures, the term carer holds no meaning in the lexicon. There is no translatable alternative that defines and describes the activity of people providing care to family and/or friends (Gupta, 2002). If the concept of carer holds no meaning it would suggest that services and support aimed at carers, using this language may, therefore, be less accessible and meaningful for people with caring responsibilities from different cultural backgrounds.

3.3 Who are carers?

People with caring responsibilities are legally defined in section 10 (3) of the Care Act (2014) guidance as: *"An adult who provides or intends to provide care for another adult (an "adult needing care")"* (*The Care Act*, 2014). This definition excludes care being provided by paid carers. Carers are relatives or friends who look after another person(s), who could not manage without their help, because of illness, disability, or frailty. The term 'carer' to describe the activities of families/friends first emerged in the NHS and Community Care Act(NHSCCA) (1990).

However it is important to point out that earlier statutes to the NHSCCA (1990) did reference the activities of people providing care without using the term carer to describe their activities. Section 8 of the Disabled Persons (Services, Consultation and Representation) Act (1986) stated. *"Where a disabled person is […] receiving a substantial amount of care on a regular basis from another person (who is not a person employed to provide such care […]) […] the local authority shall, in deciding that [decide whether the disabled person's needs call for the provision […] of services, have regard to the ability of that other person to continue to provide such care on a regular basis."* This is a relevant point to raise because it was this definition that was essentially adopted by the first carers specific statute (the Carers (Recognition and Services) Act (1995). It was the 1995 Act that sought to remedy the perceived failure of the NHSCAA (1990) to address the rights of unpaid carers.

Understanding how people with caring responsibilities were thought about in policy and academic discourses before the Care Act (2014), is, therefore, important to do, because it tells us something about the values and attitudes that existed towards people with caring responsibilities in the past. It allows the analyst to hold current debates and policy responses about this population group up to the light and scrutinise the logic and assumptions that inform the way in which they are defined as a population group who require a social-policy response. This activity is carried out in Chapter Four, where the term carer is subjected to an genealogical analysis. This draws on the third of Bacchi's six question model which asks: *'How has this representation of the problem come about?'*

The legal definition of carer, in the Care Act (2014), has shifted from earlier ones, and was viewed as a more generous and inclusive definition for the purposes of accessing support by the Association of Directors of Adult Social Care (ADASS), in their annual budget survey in 2015, because carers no longer had to be providing *" [...] a substantial amount of care on a regular basis"* in order to qualify for a carers assessment, as defined in section one (b) of the (*The Carers (Recognition and Services) Act*, 1995). Before the Care Act (2014), many LAs would quantify 'regular' and 'substantial' in relation to the number of care hours being provided per week, and some LAs had arbitrary cut-off points for the purposes of assessment (Seddon and Robinson, 2015). However, this approach was criticised by many carers' groups (Carers UK and Carers Trust), because it assumed that caring was predominantly a practical task involving physical and/or personal care that could be quantified in care hours. They argued that this did not take account of caring roles that may be emotional in nature, such as caring for a relative with mental health issues or dementia which can still have adverse effects upon the carer, such as worry, anxiety, or having to be present in order to keep someone safe but is more difficult to quantify in terms of hours spent caring. As a result of this criticism, caring became viewed as both a practical and emotional activity. Legal experts, such as Clements (2018) commented that Pre-Care Act guidance recognised that caring was more than the provision of physical and practical care. This is reinforced in Statutory Guidance (6.18) – *“Carers’ assessments must seek to establish not only the carer’s needs for support, but also the sustainability of the caring role itself, which includes both the practical and emotional support the carer provides to the adult.”* When it comes to assessments of need, it is important to stress that need takes on a particular significance, because it is not clear, in the Care Act (2014) guidance, whose definition of need drives the eligibility determination as only those carers with eligible needs will qualify for a PB. It is important to discuss how need is conceptualised in the literature such that we are able to establish the definition used in the guidance.

3.4 What is need?

Like many concepts, need is constructed widely depending upon whose interpretation is used. More modern constructions of need can be traced back to post World War Two and the creation of the welfare state. Overturning negative views of need, that were associated with the poor laws and people who were either deserving or undeserving of parish relief, is discussed in the next chapter, where the origins of family care are traced back to the 1601 Poor Relief Act. The aim being, to identify those who, through illness, injury, or disability, may need help, and, through a system of support (NHS and social care), offer benefit and help (Langan, 1998).

The British welfare state emerged from the Beveridge Report in 1942, which introduced, for the first time, a notion of ‘social citizenship’(Marshall and Bottomore, 1992). The aim being, to bring about a wider sense of belonging within society, rather than focusing upon people’s individual needs. There was a post-war consensus in Britain that wartime austerity and economic recession had taken a heavy toll on the population. Post war-reconstruction was required, and the emergence of the welfare state, with its ‘cradle to grave’ delivery model, followed on the back of the allied victory in Europe. Based on the principles of universalism, the British welfare state offered a means of care and support that moved away from the Poor Law model, of punishing those who were unable to look after themselves, to a liberal system, that established the concept of social rights, i.e. welfare rights. (Marshall and Bottomore, 1992).

It was not until the 1970s, when Britain entered an economic recession, that we saw a shift in the mind-set, away from universal welfare provision, towards the concept of affordability, and whether or not the country could continue to offer universal coverage - for all - in the face of unprecedented demand on health and social care services. It is at points like this that we see how welfare policy formation is subject to an economic context.

It was during the early 1970s, that Bradshaw (1972) developed his ‘taxonomy of need’, setting out an explanation for different types of need which has gone on to be used widely, both in academic, policy, and practice arenas. Understanding how Bradshaw defined need is worth considering in more detail, because it helps to shape our understanding of the way in which carers’ needs are mediated through the Care Act (2014) eligibility criteria, and crafted definitions of the construct. Furthermore, it is the nature, and type of need, that carers have that gives them access to public funds as PBs. Eligibility criteria are not discussed now because it forms part of the WPR analysis of the Care Act (2014) guidance in the next chapter.

Bradshaw’s taxonomy of social need set out four ‘types’ of need. The first two were felt and expressed need, which referred to subjective accounts of need, and were described by Bradshaw as an inadequate measure of ‘real need’, because the person must be aware of support and help available in order to 'express' that need (Bradshaw, 1972). In the context of this thesis, for many carers, awareness both of identity as a carer and recognition that you may have needs are frequently hidden from view (Twigg *et al.*, 1990; Twigg *et al.*, 1992; Twigg and Atkin, 1994). This is because many people with caring responsibilities do not recognise or attach the label carer to describe their caring responsibilities. They often identify themselves by their primary relationship to the person they look after, such as role of wife, partner, husband, daughter, son, or sibling. This can make it harder for carers to obtain access to help and support, if that help assumes that you recognise that caring forms part of your identity. We saw this issue identified earlier in this chapter, where cultural norms may not associate the role of families with terms such as carer. Further acknowledgment of the important use of language, in not excluding people from support because terms may hold little or no meaning to them.

It is this 'felt' or 'expressed' element of need that theories of personalisation would argue are at the heart of a person-centred model of care and support. People defining and directing how their own needs are met, being viewed as experts by experience is central to the ethos of The Care Act (2014). Therefore, it would be anticipated in phase one's WPR analysis of the Care Act (2014) guidance, that we might see evidence of how carers' own expressions of need form part of the assessment conversation and the outcomes that carers wish to achieve. Part of the function of the WPR analysis is to examine what problem is being represented as something that PBs can resolve for carers. Understanding how carers' needs are defined as part of that process will help to uncover the problem representation(s).

The third type of need defined by Bradshaw (1972) was comparative need. This sought to make comparisons of need between different population groups who receive services, for example, adults with learning disability may have different needs from, say, older adults. Or a person in their 80s, may no longer have a need for a career whereas a young learning-disabled adult may aspire for a career, and pension in later life. Lastly, normative need considered a definition of need that was described by ‘experts’ and, according to Bradshaw (1972), was more likely to reflect paternalistic norms, as professionals in decision-making roles were more likely to be middle class, educated, and articulate, in comparison with the people on the receiving end of services. In this context, ‘normative’ need may be value laden, representing the values and beliefs of, for example, the assessing social workers, rather than those of the service user or carer.

It is this concept of normative need that disability lobby groups sought to overturn and led to what became known as the personalisation movement, characterised by person-centred care that readers were introduced to in Chapter One. Central to this model of delivery, was that users of social care were able to define and direct their own care, rather than having it defined and delivered to them by what were seen as paternalistic public bodies who knew best how their needs should be met. It is through this movement that we saw the emergence of Direct Payments legislation, to give users of services more control over their lives (Needham, 2011; Ungerson, 1997).

Now that we know who carers are, and how they are defined in law, the next section moves on to consider the evidence base which explains how a caring responsibility may affect a person’s wellbeing and health. It matters to understand how the role affects people, because it is the adverse effects of caring that PBs arguably seek to mitigate. Exploring how the empirical literature defines the problems associated with caring will help inform phase one analysis of the Care Act (2014) guidance.

3.5 The impacts of caring

3.5.1 Overview of the caring population in England

The caring population in England is diverse and growing. According to the 2011 Census, 5.4 million people in England are providing care to a relative or friend who is older, disabled, or seriously ill. Given that Census data are ten years old, it is likely that the caring population has grown in this decade. In fact, it is estimated that by 2030, the number of carers across the UK will have increased by 3.4million, from 2011 figures (Wittenberg, 2011). Carers UK (a national campaigning and lobbying organisation on behalf of carers) estimated, in 2015, that carers saved the public purse on average £132 billion annually, a mean of £19,336 per carer per year (Carers UK, 2015). This demonstrates the economic value of carers' contribution to the public purse. When compared alongside the £150.4 billion spent on health and social care in Britain in 2019/20 (Kings Fund, 2020), it is easy to see the resource value carers offer government and society. Given the context of COVID-19, it would be anticipated that this £132 billion figure has risen from the 2015 estimate provided by Carers UK.

Against a backdrop of increasing demand for social care and reduction in LA provision due to cuts to LA central grants (Association of Directors of Adult Social Services, 2020), the need to support family carers has never been more critical. Particularly, as the circumstances of carers' lives mean that they are more likely to experience problems with their wellbeing and health, compared with the non-caring population (Folbre and Nelson, 2000; Rodrigues, 2013).

A Carers UK (2020) research report estimated that, every day, around 6,000 people become carers. Approximately, five million people balance work with caring; and the report estimated that 600 people per day gave up their jobs to care, because the demands of combining both became too great. As a consequence, carers experience poverty and debt. The report estimated that carers lost income is approximately £11,000 per year, compared with the non-caring population (Yeandle and Buckner, 2017; Glendinning, 2008; Lin *et al.*, 2012). The impact of lost earnings and pension potential receive less attention in the empirical literature compared with the effects of caring upon physical and psychological health. Yet, the evidence is growing that the longevity of caring is an important determinant of health and wellbeing, in broad terms (Carmichael and Ercolani, 2016; Henz, 2006; Pierret, 2006). This is thought to be one of the reasons why wellbeing became a key concept that underpinned the Care Act (2014) guidance; a recognition that financial health is inextricably linked with physical and emotional health.

3.5.2 The gendered nature of caring

When we talk about the caring population, we are in fact talking about a heterogeneous population group, where the effects of caring are felt disproportionately by some groups of carers more than others. Studies that take a longitudinal design demonstrate the effect that time has both within individual carers and between different groups of carers (Carmichael and Ercolani, 2016; Garlo *et al.*, 2010; Henz, 2006; Lin *et al.*, 2012). This body of research found that differences between carer groups, based on factors such as gender and relationship between the carer and the person(s) they looked after had a consequential impact on a carer’s health and wellbeing. Female spousal carers were much more likely to report poorer health outcomes compared with female adult daughters with caring responsibilities and male carers. Additionally, Carmichael and colleagues illustrated that relationships and life circumstances prior to a caring role commencing may impact carer wellbeing and health outcomes later in the caring journey. (Al-Janabi *et al.*, 2018). An ONS Family Resources Survey conducted in 2018/19 found that a typical carer in the UK is female, with those in their 50s and 60s most likely to be providing care (Office for National Statistics, 2021).

The gendered nature of caring has been well documented by feminist writers (Barnes, 2006; Dalley, 1996; Finch, 1983; Finch, 1989; Folbre and Nelson, 2000; Ungerson, 1997), who argue that this is one of the factors that contributes to the injustice that women carers experience. The feminist literature speaks to the PoC theoretical explanation that caring can be viewed as exploitative and discriminatory.

The activity of caring is not solely a female task. However, within a patriarchal society there is a portrayal of caring as women's work and therefore is seen as low value, low status work. (Barnes, 2006; Dalley, 1996). Although men make up a significant proportion of the caring population in England (48%) according to 2011 Census statistics (Office for National Statistics, 2016), they tend to find themselves in the less intensive 'hands on' caring roles, such as shopping, cooking, and housework, rather than intimate personal care that can often have greater physical health impacts, because it likely involves, for example, lifting and moving, and handling (Twigg and Atkin, 1994; Yeandle and Buckner, 2017).

The heterogeneous nature of the caring population has led some to describe caring as a social determinant of health, because of the disproportionate effect it has on women, and people caring at the lower end of the socio-economic spectrum (Al-Janabi *et al.*, 2018; Carmichael and Ercolani, 2016; Mitchell *et al.*, 2014). Caring as a social determinant of health indicates that women, and those carers at the lower end of the socio-economic spectrum, have a higher likelihood of taking on a caring role (compared with carers in higher-income and social-class categories); but they are also more likely to be caring for longer periods of time. These are referred to as 'higher- intensity caring roles' in the literature (more than 20 hours of care per week) (Al-Janabi *et al.*, 2018; Carmichael and Ercolani, 2016; Mitchell *et al.*, 2014).

3.5.3 Caring as a social determinant of health and wellbeing

Caring as a social determinant of health is beginning to receive some traction in the literature, where the evidence paints a picture of income and social class as important determinants of inclusion and participation in economic and social life, for carers. Newcastle University was commissioned by Public Health England to explore the consequences of being an unpaid carer to older people, and to identify evidence about how best to support this group of carers. The University carried out a rapid review and analysis of GP Patient Survey. Their main findings, published in March 2021, provide further evidence that caring should be considered a social determinant of health. Caring is not, and has never been, considered from a public health perspective, despite the weight of evidence that carers are at greater risk of poorer health and wellbeing compared with the non-caring population, where intensity and duration of caring, over time, is considered an important determiner of carer health and wellbeing (Al-Janabi *et al.*, 2018; Carmichael and Ercolani, 2016; Mitchell *et al.*, 2014).

3.5.4 Intensity of caring

The relationship between the number of care hours provided and the effect on health and wellbeing is reported on by research, from Verbakel *et al.* (2017) and Roth *et al.* (2009). For instance, Verbakel *et al.* (2017) reported that women carers between the ages of 50 to 59 were more likely to find themselves in higher intensity caring roles (defined as 15 hours per week or more), compared with male carers in their analysis of survey data from a European social survey. The robustness of their analysis is supported by the large cross-national (20 countries) sample size (n=28,406) It is noteworthy that there is a lack of consensus on the meaning of intensive care giving, because Carmichael and Ercolani (2016) defined intensive as care ≥ 20 hours per week whereas Verbakel *et al.* (2017) defined it as ≥ 15 hours per week.

This suggests that gender, the number of weekly care hours, and length of caring role, are important characteristics that contribute towards a carer's health and wellbeing. It also suggests that they influence the extent to which carers can participate in economic and social life. The greater the number of hours you care for, the harder the likelihood of maintaining paid employment, particularly if you are expected to leave the home for work.

As well as the disproportionate gendered effects of caring on women, there is empirical evidence to suggest that income and social class are important social determinants of a carer's life experience. The empirical evidence base on the effect of social class in relation to caring is limited. However, Arber and Ginn (1992) suggest that social class is an important characteristic in understanding the effects of caring on health and wellbeing. That is because more people care for relatives who find themselves in the lower income and social class groupings because there is a higher incidence of disability and ill health in these population groups (Dahlberg and McKee, 2016). Given, that the social gradient in health is widely accepted, as evidence that people, who are less advantaged in terms of socio-economic position, have worse health and shorter lives than those who are more advantaged, it is surprising that there is a paucity of literature on social class and caring. This provides further evidence for the consideration of caring as a social determinant of health.

What this discussion, on the caring population, points to, is the relationship between factors that contribute to caring as a social determinant of health (gender, and socio-economic position), and the degree to which carers are able to exercise choice and control over their lives. The progression of the discussion is that carer heterogeneity (being female and at the lower end of the socio-economic ladder), shapes the degree to which you have choice over whether you take on a caring responsibility and the intensity and length of that caring role. We have found that women, and those at the lower end of the socio-economic spectrum, are not only more likely to become carers, compared with men and those on higher incomes, but that they are also more likely to find themselves in the higher-intensity caring roles (15≥ hour of care per week) (Al-Janabi *et al.*, 2018).

The longer you spend caring for, both in terms of hours per week and over the lifetime of your caring role, the harder it will be to obtain and maintain employment with caring. That may go some way to explaining why more than 600 carers give up their jobs every year. Not being able to work will likely impact your financial wellbeing if you rely upon carers' allowance as the main income replacement for people caring for 35 hour per week or more.

This discussion begins to call into question the ability of PBs to be able to act as a lever that can promote carer wellbeing, when the caring population is heterogeneous, and provides further weight of evidence towards the need to scrutinise the impact that PBs are having on carers lives, by comparing their roll out and effect with the intentions proposed by the Care Act (2014)guidance.

3.5.5 Relationship between social determinant of caring and choice and control

One of the reasons why income and class are important to carer health and wellbeing, is because carers in lower-income-and-class categories have less choice and control over decisions about whether to care, and the extent to which they are able to participate in economic and social life, compared with higher-income-and-social class categories of carer. This position is supported by (Al-Janabi *et al.*, 2018) who carried out a postal survey of 1,110 carers. They found that choice over whether to care is mediated by factors such as income and social and cultural norms over family responsibility for the provision of care. Here, we see reference to the ethics of care theoretical perspective being used to explain why it is the norm for families to be the main providers of care.

Yet, Al-Janabi *et al.* (2018) and colleagues' findings go further and suggest that people at the lower end of the income scale are more likely to take on caring roles compared with people in higher paid jobs. Respondents in higher earning households were more able to consider how paid carers could support them in their role, so as not to compromise their earning potential or career.

These are important findings, because they suggest that factors such as income and class may affect a carer's ability to participate in economic and social life, more than caring itself being a barrier to participation. People who are already struggling in precarious employment, or who are unemployed, are more likely to take on caring roles than those who have better, more secure access to the labour market. In previous research (MSc dissertation findings – unpublished work) I examined factors that contributed to carers feeling socially excluded, using longitudinal data from the UK Longitudinal Household Survey (UKLHS), and found carers, in lower-income and social-class categories, were more likely to report feeling socially excluded compared with carers in higher-income-and class categories (Chard, 2017).

3.6 Summary

This chapter has operationalised some of the key terms used in this thesis as a basis for foregrounding phase one's WPR analysis of the Care Act (2014) guidance and narrative synthesis of the literature. It has shown that carers are not a homogeneous population group, and, therefore, begins to cast doubt on PBs as a lever that can promote the wellbeing of all carers as a population group.

It is within this backdrop of a growing understanding that social care responses need to be more individualised, that legal and policy responses and solutions to the problems associated with caring have developed over time. The purpose being to increase carers' rights to recognition and support. This has led to the enactment of the Care Act (2014) in April 2015. The political commentary, in the guidance accompanying the Care Act (2014), positions PBs as a mechanism that can deliver personalised and individualised responses to carers based upon their individual circumstances.

In the next chapter, the discussion moves on to consider a genealogical analysis of the term carer, to understand when it was first possible to use it in policy and public discourses. One of the aims of the genealogical analysis is to foreground phase one of the examination by the thesis of the intentions behind PBs as a policy solution to the problems that carers experience. By looking back in time, to see how the activity of caring has been understood in policy discourses, it is possible to chart a timeline to illustrate the values and ideology that shaped discourses about caring through a historical lens.

Chapter 4 – A Genealogy of Caring

4.1 Introduction

This chapter sets out to address the third question in the WPR six-question model, devised by (Bacchi, 1999; Bacchi, 2016). The first two questions in the WPR analytical framework are addressed in Chapter Five, which identifies what the problem of caring is represented to be within the Care Act (2014) guidance, and the assumptions that underpin the way in which caring is problematised. As a reminder to readers, section 1.3 on pages 21 and 22 and table one on page 23 explain why this thesis is applying the WPR questions in a non-sequential order. The rationale being that, by starting with question three, it is possible to establish a policy timeline to chart the politics involved in the formation of historical policy responses towards families, and how those responses shaped attitudes and values towards caring as an activity. Starting with question three, therefore, foregrounds the next chapter's WPR analysis of the Care Act (2014) guidance, because it demonstrates how Care Act (2014) guidance is shaped and influenced by preceding carer policy and statutes, and the role of politics in those policy formations.

Historical accounts of carer policy draw from the third question in the Bacchi model of policy analysis, which asks, *"How has this representation of the problem come about?"* It does this by applying Foucault's thinking on the genealogical nature of knowledge. Genealogy refers to the process of going back in time to examine how historically-constructed knowledge can help us to understand and hold up a mirror to the meaning we give to present day knowledge (Bacchi, 2016).

This chapter starts by identifying how caring became produced as an object for thought.

4.2 What do historical accounts of caring have to tell us?

Looking to the past adopts a problem-questioning approach, which constructs problems in a specific historical context, thinking beyond laws of causation, prediction, and deduction (Glynos, 2007). This means exploring how caring became an object that necessitated a social policy response, by revisiting when it was first possible to talk about caring as an object of public and political discourse. That is why a Foucauldian-informed genealogical analysis is helpful in examining the historical roots of caring, as a concept, and how it has become constructed over time, and the meaning created by those constructions.

A further purpose of looking at caring from a genealogical perspective helps to understand the values that are held today about caring as an activity. In other words, genealogy submits the present 'truths' about caring to historical scrutiny, and locates them, instead, at the level of practices. Practices are places where *"what is said and what is done, rules imposed and reasons given, the planned and the taken for granted meet and interconnect."* (Foucault and Rabinow, 1984, p. 75). The genealogical process involves looking at the way in which language about caring has been constructed over time, examining how the knowledge produced shapes social policy and practice towards people with caring responsibilities. The rules imposed by a particular way of framing people with caring responsibilities and the reasons given for those rules form a particular practice. These practices establish social norms.

This approach offered up the opportunity to ask important questions about what had happened, in order to put our taken-for-granted assumptions about the role of families in the provision of care up for display. How had we come to think about carers and caring in the way that we did? For example, that families feel a sense of responsibility and duty for the provision of care, or that carers are called 'unsung heroes' for their perceived self-sacrifice or are a group of people we have sympathy for because of the impact caring may on their lives.

Why do we categorise people as carers, and how has caring been narrated through time? By doing this, it is possible to see how caring may have been viewed differently over time, and, therefore, offer up alternative constructions of caring (ways of talking about the activity) that challenge dominant public discourses of caring that exist today.

In examining historical accounts, Foucault wanted to emphasise a relationship between knowledge and power. Power, to Foucault, is involved in the production of knowledge, and the language we use reflects that knowledge. Words hold power (Bacchi, 2016).

In this context, Foucault describes power as both productive and negative. What he means by this is that power is active and dynamic. It is not a fixed concept, unable to change hands, but rather it can shape people's understandings of themselves, and, therefore, can be considered positively as well as regressively. An example of the positive productive nature of power might be the 'me too' movement, where women have taken on powerful men and institutions which has led, in some cases, to positive change . But which itself is also rooted in, and drawn from, prevailing patriarchy, such that there has been a shift in power from one countervailing force (toxic masculinity), to another, powerful force – 'me too'. Therefore, knowledge as a source of power, can influence the position a person takes in relation to something. Foucault refers to this as a *'subject position'*. One of the subject positions that carers take, which is evidenced in the next section, is responsibility (responsibility for the provision of care).

From Foucault's perspective, it is possible for carers to take different subject positions, if they are exposed to different knowledges. It is by tracing the history of caring, as an object of policy, that we are alerted to the possibility that caring, as a practice, may have been considered and could be thought about differently (Bacchi, 1999). This process opens a space to consider caring from alternative perspectives, other than those that occupy the public and political discourses now. Foucault refers to these as '*subjugated knowledges'* – those that have not been given the light of day (Bacchi, 2016; Foucault and Rabinow, 1984).

The productive elements of power allowed me to question why some ideological and political practices gain more traction than others in the policy-making process. For example, why EoC (Gilligan, 1993; Noddings, 1992), with their focus on care as a loving, dutiful, and responsible act, have more influence, and shape the policy and academic discourses more than PoC perspectives (Tronto, 1993; Tronto, 2017), which consider the discriminatory effects of caring, particularly on women. Or, how theories of personalisation, which first introduced the concept of PBs as a mode of social care delivery, were able to dominate the social care landscape, and become accepted as 'truth', that they facilitate and enable people to have a greater degree of control over how their care and support is defined and arranged, than they otherwise would have had without a PB.

By taking a problem-questioning approach, the focus shifts to one of how policy becomes an emergent process (Bacchi, 2016), one that is shaped by former and ongoing interactions with discourses, which can be revealed by Foucault's genealogical method.

The next section focuses on identifying when caring, as an activity, first became an object of thought in policy documents to describe the activities of families providing care.

4.3 How has this representation of the problem of caring come about?

If we think about caring as an object of thought, it has been a fundamental feature of human relations since the early humans. Social bonds, involving care for infants, sharing food and resources were fundamental to survival in hostile environments (Smithsonian Institute, 2020). So, the idea that care and caregiving is something that only existed because laws and policies decreed it so, is not what is being suggested here. Rather, our meaning of how we understand what a caring role involves (specifically when care involves looking after an ill or disabled adult), is shaped by knowledge that is produced through language. It is the use of language in policy documents to define and describe caring activities that is the focus of phase one of this thesis. Specifically, it is to understand how that language has evolved over time, in a policy context, to reveal policy solutions and the assumptions that indicate what it is that needs to change in order to improve the lives of carers.

4.3.1 When was it first possible to use the term carer in public and policy discourses?

The origin of the role of family in the provision of care in statute can be traced back to the 1601 Poor Relief Act, which placed a legal duty (for the first time in public law) on families to provide care for the weak and vulnerable. Often referred to as the 'family law', caring was viewed not as a social problem but rather more of a legal and moral obligation that families had towards one another. The 1601 Act drew a distinction between the '*impotent poor'*, those who were unable to work (referred to as the *old*, the *blind* and the *lame*), and those who were '*able bodied'* poor, often considered idle and work shy, and, thus, subject to punishment rather than concern (Beresford and Alibhai-Brown, 2016; Clements, 2013).

Families were seen as primarily responsible for the provision of care because public assistance, through the Act, was only available after a relative's contribution was considered. Of course, definitions of care were also historically contingent. There was no concept of wellbeing, and its relationship to care and health, in the 17th Century, like we have now. The focus of care was one of subsistence and survival. Prosecutorial provisions were laid out for relatives who refused to look after the 'impotent poor'. Relatives named in the 'family' Act were parents, grandparents, and children. Children were seen as being equally responsible for their parents (if parents were defined as impotent poor), as they were for them (Abbott, 1938;

Bailey, 1975; Beresford and Alibhai-Brown, 2016). Section 6 of the Poor Relief Act, 1601, provided that: *"the father and grandfather, and the mother and grandmother, and the children, of every poor, old, blind, lame and impotent person, […] being of a sufficient ability, shall at their own charges relieve and maintain every such poor person…."* (Abbott, 1938, p. 22). This quotation from the S6 in the Poor Relief Act (1601) illustrates the emphasis placed on families' members to not only house their relatives, who were unable to look after themselves, but, also, to financially support them (Abbott, 1938).

The responsibilities of children, for the provision of care, in this extract illustrates, once again, the historically contingent meaning attached to language. The meaning of childhood in the 17th Century was not what it is today. There was no separation of childhood as a distinct life phase, from adulthood, or any need to protect children from the privations of work and maintaining oneself and family.

Reasons for the provision of filial laws within the Poor Relief Act are debated. Stuifbergen and Van Delden (2011) argue that the primary reasons are philosophical rather than community oriented (e.g., cost avoidance), for such obligations towards families to provide care. That it is not simply a question of saving governments money by obligating families to provide care. They come to this position by reviewing what they term theories of filial obligation (reciprocity, friendship, and need/vulnerability). Or, as we have come to know this, as an EoC theoretical framework (Gilligan, 1993; Noddings, 1992; Noddings, 2002) which defines care and caregiving by its reciprocal and friendship ties that bind people together and infer obligation in response to giving. As already discussed, these obligations explain the meaning of care and caring from the context of a reciprocal loving relationship between people.

In contrast, Abbott (1938) took a different view, and saw the imposition of filial binds in the 1601 Act as a direct attempt to move the cost of care onto the family. Before the 1601 Act, support for the poor and vulnerable was largely seen as a charitable endeavour. Adopting a collectivist approach, the *'impotent'* poor were often looked after in what were termed '*cottages*', and it was the responsibility of the Church to collect money from local communities, called '*parishes*', on a voluntary basis to provide support. Abbott (1938) suggested, that the problem of '*beggary*' and 'v*agrancy*' had become too acute a problem to be left to charity and religious foundations alone, and that was a key reason why the Poor laws were established. She also suggests that filial binds reflected social norms and values of the day, which were associated with the legal and enforceable duties that husbands had towards their wives.

Women were seen as incapable of performing any legal act, and common law, at that time, placed husbands under a legal obligation to supply their wives with *"necessaries*" for existence, and duties of parents to provide for the maintenance of their children was considered a "*principle of natural law*" (Abbott, 1938, pp. 22-25). The implicit assumption was that the state did not want to be burdened with the cost of keeping families. Of course, during the 17th Century the understanding of government and the state was very different from the role of government in family life today. Yet, what this picture revealed, was a sense that there existed a moral obligation upon families which existed outside of common or civil law. Poor laws provided only that the parents, grandparents, and the children of "*being of sufficient ability*", should *"at their own charges, relieve and maintain"* the poor relative who was unable to support themselves (Abbott, 1938, p. 22).

Later, financial support developed into compulsory taxation (poor taxes), and cottages evolved into Workhouses for people without family or those whose families were unable/unwilling to look after them (Bayley, 1982; Beresford, 2016). A clear line was drawn between the deserving and undeserving poor, based upon the categorisation of impotent versus able-bodied poor. Objections to the filial responsibilities were, that the people expected to care were often impoverished themselves, and not in a position to maintain others beyond themselves and immediate families. So, it was not that they were morally bankrupt, but, rather, did not have the financial means to support themselves, let alone anyone else. The 1601 Act referred to families as the *'liable relative',* and this term persisted through to the creation of the welfare state and the National Assistance Act (1948).

What we can take from this description, so far, is the meaning created by language in the 1601 Act, which established that families are responsible for care. The role of the state was secondary to that of the family in providing help and support for family members who needed it. This, of itself, is not unusual, because there was no welfare state in the 17th century. But what it does do, is to reinforce the position of policy as discourse. It signals a shift from the collectivist principles that predated the Poor Laws, where care was viewed as the responsibility of the parish, through voluntary donation, to one, where the individual accepts obligations laid down in public law, but also in 'natural law'. The insertion of 'natural' law into the 1601 Act implies a moral obligation as well as a legal obligation to care.

The inclusion of moral or natural laws between family members in the Poor Relief Act is problematic because it reflects more the dominant values of the day than any sense of a fixed, objectivity or neutral, account, about what responsibility is, or should be. This is evidenced, for example, in the way that children were viewed as equally liable for the provision of care for their parents if they became impotent poor; or that women were viewed as their husband's responsibility and property, because they were considered incapable of looking after themselves. Having said that, as has been discussed already, there was no conception of childhood during this period, as we know it today. No distinction was made between children and adults in any developmental or cognitive sense of the word.

Moral philosophy, during the time of the Poor laws, emerged from utilitarian philosophies led by Jeremy Bentham. Utilitarianism is an ethical theory that holds the position, that actions are morally right if they promote the greatest happiness and/or utility for the greatest number of people (Sandel, 2010). So, if some people are disadvantaged by, for example, by the way in which a society distributes income, wealth, and rights then so be it, as long as the ends serve the needs and rights of the majority (Sandel, 2010). In the context of the Poor Relief Act (1601), the inherent appeal of taking a utilitarian approach to the poor and those unable to take care of themselves is that the greatest good may be served by families providing care for those who were unable to care for themselves. However, the problem with that approach is that it takes no account of the effect that that may have on those with caring responsibilities. It is simply that the cost to the carer is less than the cost to the cared-for.

In the context of the Poor Relief Act it presupposes that everyone has the same capacity to provide care for those that need it, and clearly that was the not the case during the 17th and 18th Centuries, as we know that cottages turned into Workhouses for the poor and destitute, as many families could not afford to look after them, and filial care really meant care by women. Filial binds were to become viewed by women as the site of their oppression in the domestic private sphere (Alcock, 2008; Beresford and Alibhai-Brown, 2016; Dalley, 1996).

Filial responsibility for the provision of care persisted right the way through to the National Assistance Act of 1948, which removed the legal duty from families, which coexisted alongside the development of the post-war Welfare State, and the establishment of a state apparatus in the form of health, social care, and social security provision (Alcock, 2008; Beresford and Alibhai-Brown, 2016).

The National Assistance Act (1948) abolished the Poor Laws and made the relief of the poor a national, rather than private, responsibility. It removed the obligations of children towards their parents in the matter of maintenance, and termed '*liable*' relative to mean both men and women who had equal financial responsibility towards each other in marriage. It represented an attempt to equalise the inequity of the past and recognise women as people who were capable of economic independence from men.

It is possible to see how the establishment of a more liberal political ideology removed the duty from families, to provide care, and instead, placed responsibility on government for the provision of care and support for the sick and disabled. As the Poor Laws were exported to the colonies, many countries today still carry filial responsibility for care in their statutes, including a number of American and Canadian states (Clements, 2013). It is possible in some countries today for adult children to be compelled to care for their ill and/or disabled relatives or face prosecution for refusing to do so.

With the advent of the British Welfare State, families were no longer compelled to provide care. According to Baldock (2012, p. 22) *"...the welfare state was at one time understood as the twentieth century's most complete answer to social need."* Government rather than citizens, took responsibility to provide care. People who needed care and support would be able to receive care and support based upon principles of egalitarianism. The idea being that people could make choices from a position of equality because everyone would have access to the same level of care, free at the point of delivery, and not dependent upon ability to pay.

At the same time this philosophy of egalitarianism was not without its critics. Keith Joseph, a key influence in the creation of what became termed 'Thatcherism' argued that egalitarianism led to a decline in the will and ability to create wealth, and he believed that the welfare state represented a coercive interference by the state. Joseph supported the concept of a social-market economy, which is a socio-economic model that combines the principles of free-market economics with a market orientated welfare state (Turner, 2008). An alternative view was that the self-interest of individuals can further the welfare of others. It should not be left to the state to interfere in the private lives of its citizens (Mead, 1986; Murray, 1984).

Freedom-based theories, like Joseph's; Mead's and Murray's reflect a libertarian philosophy of justice that means respecting individual freedom of choice and self-determination. Freedom based theories are often connected with the concept of responsibility. From this perspective, in order to gain rights, you must also contribute something in return. Critics of the post-war welfare state Mead (1986) and Murray (1984) argued, that it offered unconditional support in the form of benefits but asked little in return. *"Only those who bear obligations can truly appropriate their rights"*(Mead, 1986, p. 257). From this perspective it could be argued that carers bear great obligation on behalf of the state, and minimal rights are conferred upon them as a result.

One of the principles of the welfare state was to promote the health and wellbeing of citizens through a joined-up system of interlinking parts that offered free education, the establishment of the NHS, public housing, and a national system of social insurance benefits for all in need, which was established through the National Assistance Act (1948).

The National Assistance Act (1948) established a social safety net for those who did not pay national insurance contributions. Examples cited in section 29 (1) *" A local authority shall have power to make arrangements for promoting the welfare of persons to whom this section applies, that is to say persons who are blind, deaf or dumb, and other persons who are substantially and permanently handicapped by illness, injury, or congenital deformity or such other disabilities as may be prescribed by the Minister."* (*The National Assistance Act*, 1948).

What we saw evolving, through the development of the British welfare state, was a rights-based model of welfare which was in contrast from the poor laws which sought to police people's need for care and support, both morally and legally. A guiding principle of universalism was introduced to counter the stigma of the Poor Law, resulting in means testing those who are deserving of help, versus those who are not. Entitlement for all, irrespective of means or circumstances, based on a national insurance payment, that all working citizens would contribute to, still exists today.

The concept of welfare as a right or entitlement rather than act of charity saw a provision of welfare that promoted the economic and social wellbeing of its citizens beyond their immediate needs for health and social care. This was best articulated by T.H. Marshall, a sociologist in the 1950s, who introduced the concept of social rights, which he understood as being people's right to welfare. (Beresford and Alibhai-Brown, 2016, p. 87) writing about Marshall, described: *"he believed in an evolution of rights in England acquired through citizenship, beginning with civil rights in the eighteenth century, political rights in the nineteenth century and social rights in the twentieth".*

Meeting the social needs of citizens was valued as a public good and separated from profit-making. Removing the stigma of poverty, illness and disability were key features of this approach. (Beresford and Alibhai-Brown, 2016) talk about this as a social relationship between citizen and state, where the state accepts a social responsibility. They provide goods and services, not out of charity, pity, nor a moral judgement of deservedness, but, rather, out of entitlement as of right.

The principles of universality, however, did not mean that everyone got what they needed nor that people were treated equally. The Social Service functions of the welfare state met the need of those who through illness or disability could not meet their own needs. The National Assistance Act (1948), unlike the NHS, did not provide the Social Services functions of the statute free at the point of delivery. People requiring social care were expected to contribute towards the cost of their care.

We saw in the previous chapter how Bradshaw's typology of need, and, in particular, normative definitions of need-shaped, paternalistic, top-down responses to support that which the disability right movement sought to counter.

However, critiques of Bradshaw's model suggest that the legacy of the poor laws still lived on in the long-stay hospital and psychiatric institutions, which did little to advance the rights of marginalised groups, such as those who experience mental ill health, learning disability, and older adults. Evidence of institutional abuse and neglect emerged during the 1960s and 70s. The work of Townsend (1962), which evidenced the restricted lives lived by older people in long-stay hospitals, and Goffman's seminal text *Asylum*, catalogued the abuses experienced by people in long-stay psychiatric institutions (Goffman, 1961) The growing empirical evidence of neglect and abuse shone a light on the awful conditions that people who were ill and disabled were experiencing.

This heralded as an important shift in policy towards community care being a more humane system, providing care closer to people's own communities in environments that looked and felt like a home. Yet, the construction of the term community is a contested one (Crow, 2011). People can mean different things when they talk about community, therefore, it is important to make sense of the way in which community has become understood, as an entity that supports people who require care and support in a way that promotes their human rights, to dignity, autonomy, and respect, which was one of the key criticisms of institutional forms of care.

The construction of community care, as an entity supporting people's independence from others, including institutional forms of care is where we turn to next.

4.3.2 The social construction of community care

It is important to stress that the shaping of community care in the 1980s and 1990s was not simply a response to the mistreatment of people living in institutions, but, also, a growing political ideology of individualism and shift away from collectivism. This was best captured by an interview Margaret Thatcher (then Prime Minister of the UK) gave to a well-known women's magazine, Woman's Own, in 1987: *"There is no such thing as society. There are individual men and women, and there are families. And no government can do anything except through people, and people must look to themselves first. It's our duty to look after ourselves and then to look after our neighbour"* (Keay, 1987). Thatcher was influenced by the thinking of Friedrich Hayek, who argued that social institutions are shaped by spontaneous evolution, rather than by intellectual design. Hayek saw society as a system of inter-dependent social systems that brought their own natural order to human lives. This evolving order allowed individuals to express personal choices, and by those choices, systems and institutions are shaped and continuously evolve (Yueh, 2015).

Individualism became synonymous within a welfare context to mean individual freedom and choice. Hayek, an economist, and philosopher, was best known for his belief that private investment, rather than government spending, would promote sustainable economic growth. This view was to have a significant impact on the role of families, in the provision of care, as the NHSCCA (1990) introduced significant reform, both in how and who delivered care to people who were ill and disabled.

The NHSCCA (1990) brought about a shift in focus from the state as the provider of care to the community. Private, charitable, and informal care were to play a greater role in the provision of care. LAs were to become enablers. Social Workers became care managers who arranged packages of care, but informal care became the mainstay of this policy reform (Barnes, 2006; Heaton, 1999). It is interesting to note, that the empirical literature during this period appears to make no suggestion of a relationship between the construction of caring as an object of policy discourse, and the moving of care, away from long-stay institutional settings, into the community, such that care could be provided closer to home, effectively, meaning that care was being provided by the community, and, therefore, by families (Heaton, 1999). However, when you look at some of the policy documents that preceded the NHSCCA (1990), it appears to imply just that.

To use a phrase coined by Bayley (1983), '*community care'* came to mean not only care *in* the community, but, also, care *by* the community. This shift was clear in policy by the 1980s, as the following statement from the White Paper *Growing Older* indicates in section 3 (1):

"Whatever level of public expenditure proves practicable, and however it is distributed, the primary sources of support and care are informal and voluntary. These spring from the personal ties of kinship, friendship, and neighbourhood. They are irreplaceable. It is the role of public authorities to sustain, and where necessary, develop-but never displace-such support and care" (Department of Health, 1981).

The reference to family, as informal carer in the NHSCCA (1990), is implicit. It does not connote caring as a social-policy problem, at this time, and no provision was made for family carers in this implicit new role. It would seem more than coincidental that the closure of long-stay institutional forms of care would coincide with the emergence of the term 'carer', to refer to primary sources of care and support as informal and voluntary. It also creates the idea that communities were ready and willing to provide care.

Feminist critiques of community care policy, at this time, were concerned by the reference to informal care referring to families. Feminist writers, such as Ungerson (1997), critiqued the NHSCCA (1990), and concluded that community care, as a policy, rested on the assumption that women were natural carers and would be able and willing to replace paid carers from institutional settings. *"Care in the community equals care by the family equals care by women"* is how French and Groves cited in (Parker, 1990, p. 87) described the reforms during this decade.

Factors, such as demographic change and welfare recidivism, that accompanied an individualistic, neoliberal, market-based model of welfare provision (Deeming and Smyth, 2015; van Hooren, 2012), have seen a significant increase in the numbers of people providing unpaid care in the UK (Clements, 2013). Neoliberal, market-based models of welfare are debated in the next section, because there are several positions from which neoliberalism, as an economic and political philosophy, can be considered in relation to welfare provision. It was during this time period that the first carer specific statute was enacted in 1995.

4.3.2.1 Carer specific legislation

It was not until 1995 that people with caring responsibilities were written into statute in their own right with the Carers (Recognition and Services) Act. This gave carers, who were providing regular and substantial care, a legal entitlement to ask for their own assessment. Prior to this, carers were largely ignored by LAs, and although there were provisions within the NHSCCA to assess the needs of carers, the practice was patchy, and ad-hoc, at best (Twigg *et al.*, 1992; Twigg *et al.*, 1990; Twigg and Atkin, 1994). This was quickly followed by two further pieces of legislation, the Carers and Disabled Children Act (2000), and the Carers (Equal Opportunities) Act (2004). Each piece of law intended to improve on areas the previous law missed. For example, the 2001 statute gave LAs a power to provide services to carers following assessment, as the 1995 Act was purely an assessment statute and nothing more. The 2004 statute placed a duty on LAs to inform carers of their right to an assessment, as the evidence suggested that few were being offered one (Heaton, 1999; Nolan, 1994; Thompson, 2000).

The NHSCCA (1990) instantiated market principles into a Beveridge model of health and social care, which was positioned as a way to improve choice for service users and carers (as consumers of services), but, also, to drive up efficiency through competition between providers. The contracting culture was viewed as one of the influencing forces behind the personalisation agenda (Clements, 2013; Deeming and Smyth, 2015). The idea, that service users should have individualised care plans and have a greater degree of choice and control over how their needs were defined and met using PBs.

The influence of political ideology cannot be ignored in debates about care and care-giving, and it is important to consider this influence because the aforementioned discussion clearly shows how political ideology, of collectivism versus individualism, shaped the extent to which families became involved in, and responsible for, the provision of care as has been demonstrated by the introduction of the modern welfare state in 1945, and the removal of filial binds which shifted responsibility away from the family and onto the Government for the provision of care.

4.3.3 The rise of neoliberalism in a policy context

What has been established, so far, is that an individualistic view of community care emphasised the role of family as well as friends and neighbours as the main providers of care. This period is often described by some commentators as the beginnings of the neo-liberal welfare state (Clements, 2013; Deeming and Smyth, 2015), because it reflected the reducing role of government influence in the provision of public services and a greater reliance on the family or individual as privately responsible for the provision of care. The decades that followed the NHSCCA (1990) saw the creation of the Carers Centre model of delivery to support the needs and right of family carers. This building-based model of advice, information, and support exists today, with most cities and towns providing some sort of carers' service through the voluntary and community sector affiliated to The Carers Trust, which provide a network of support to individual centres.

Having said that, there is a lack of consensus on what neoliberalism is, and Bell and Green (2016) suggest caution on applying the concept as a catch-all phrase to represent a marketisation of public services. They draw on the work of Ward and England (2007), to highlight the different understandings and applications of neoliberalism in social science research. They posit four key understandings: 1) That neoliberalism is an ideological hegemonic project. In other words, it represents a dominant set of ideas that govern society. 2) Neoliberalism as policy and programme, for example, it could be suggested that the Care Act (2014) represents a policy programme under the banner of deregulating care, away from the state and LAs and into the hands of communities and families. 3)This relates to the third understanding, that neoliberalism represents a form of the state i.e. the 'rolling back' of state involvement in welfare provision, or the 'rolling out' of privatised forms of welfare provision (Bell and Green, 2016). This enables the reader to imagine policy formation as a political process, emerging from the interaction of political ideas, interests, and values (Smith and Katikireddi, 2013). 4) The final understanding is one that Foucault describes as neoliberalism as governmentality –how relations between peoples are interpreted in ways that create a form of governing (from a distance). The WPR model of policy analysis uses Foucauldian principles of governmentality practices, to understand and explain how policy solutions, like the Care Act (2014) become ways that govern how social workers practice and how carers come to understand their role, and what is possible to say and do in relation to that role, as opposed to a view of policy formation that proposes governments react to societal problems and do their best to solve them. Neoliberalism as governmentality implies that governments (all of us) give a particular shape to a problem in the way that we speak about it, and in the proposals we advance to address those problems. From this view, governments become active in the creation of problems as particular types of problems.

4.4 Summary

What this chapter has shown is that governments have not produced carers. Citizens have always provided care within different contexts. We have seen that, through the genealogical analysis of caring, where churches provided care to people prior to the Poor Laws, that families were given that responsibility during the 17th Century. Rather, that government policies produce caring as a particular sort of problem. Carers become problematised in particular ways. The way in which the problem is produced, within a specific policy, is part of how carers become governed by that policy.

The next chapter moves on to consider the ways in which caring is constructed as a particular problem that can be solved by accessing PBs. This is achieved by addressing questions one, two, four and five of the WPR method.

Chapter 5 – Phase one – Intentions of the Care Act (2014): A WPR analysis of the Guidance

5.1 Introduction

In the previous chapter, we saw how a genealogy of caring showed the role that political ideology played in the shaping of policy responses towards people with caring responsibilities. Shifts, from collectivism towards individualism in the establishment of the Poor Laws and filial binds, towards collectivist principles with the advent of the modern welfare state and removal of family responsibility for the provision of care, evidenced how governmental responses through legislation influence people's behaviour. It was the move towards community-based forms of care, through the NHSCCA (1990), that we saw the creation of the term carer to describe the activities of families supporting ill and disabled family and/or friends. The advent of community care policy, again, indicating clearly that care in the community equalled cared by families.

Community care policy, once again, shifted significantly with the introduction of the Care Act in 2014, signalling a shift in policy terms for carers with the establishment of PBs as a right for carers who met the national eligibility threshold for support. PBs were positioned as a lever that would offer carers greater flexibility and choice, in terms of being able to shop around for different products and services to support them in their caring role. But they were also being positioned as a lever that would give carers a greater deal of control over their own lives, because the guidance implied that PBs would facilitate a carers' participation in economic and social life and therefore a recognition that caring could impede a person's wellbeing and health.

This chapter addresses phase one of the thesis and research question, that asks: *'What are the intentions behind PBs as a policy solution to the problem of caring?'* This is achieved by addressing four of the six questions in the WPR analytical model. These are: 1) *What is the problem of caring represented to be in the Care Act (2014) guidance?, 2) What assumptions underlie this representation of the problem of caring?; 4) What are the silences?* and *5) What effects are produced by this representation of the problem?* (Bacchi, 1999)

The first section of the chapter offers a background and context to the Care Act (2014). This is important scene setting because it gives readers an understanding of the political, social, and economic context in which the Act was created. This context matters because it shows how the Act came about, not in response to a specific policy challenge, such as a public health crisis in relation to carer health and wellbeing, but, rather, the result of prevailing economic and political philosophy (Whittington, 2016). In the same way that the genealogy of caring, in Chapter Four, demonstrated how the social construction of caring and need were a response to political ideology, in shaping attitudes and values towards welfare and care, and who should provide it.

This background and context provide a backdrop and methodological rationale (in the second half of the chapter), for the use of WPR as an analytical framework from which to analyse the Care Act (2014) guidance. Policy formation from this perspective is viewed as a political rather than rational process (Shaw, 2010).

Finally, the chapter concludes with a WPR analysis of the Care Act guidance. It does that in two ways. The first, is a critical analysis of the care and support sections of the Act which detail the intentions behind PBs as a policy solution to the problem of caring – they are:

1. Parity of esteem (same entitlement as service users) for carers via access to assessment, based on the appearance of need.
2. Greater sense of choice and control through outcomes-focused carers' assessments and support planning conversations.

3. Promoting wellbeing (encompassing participation and inclusion) through the administration of PBs for carers who are found to be eligible following a needs assessment.

Are these intentions reflected in the language used within the guidance accompanying the Care Act (2014)? The sections of the guidance assessed were duties and powers in relation to carers' rights to assessment of need, eligibility for PBs, and support through PBs. The second mode of analysis holds wellbeing as a concept up for critical scrutiny, by applying the WPR method. As Bacchi (1999) states, concepts can be thought of as proposals too, and, therefore, can be subjected to scrutiny in the same way that policies are.

The reason for applying a WPR problem-questioning approach to wellbeing at a conceptual level, is because the meaning of wellbeing and the ways in which it is operationalised within the Care Act's (2014) guidance, are of critical importance to be able to answer the overarching research question posed by this thesis, about whether or not PBs can promote carer wellbeing. To be able to address the purpose of this thesis, to assess the extent to which PBs promote wellbeing, one must have a detailed understanding of what wellbeing is: how it is conceptualised and applied in policy discourses.

5.2 Background and context to the Care Act (2014)

It was established in chapter one that the Care Act (2014) signalled a significant reform of adult social care. Moving away from paternalistic, top-down modes of support, towards a person-centred model, where PBs were viewed as the method to achieve a more personalised care and support system (Feldon, 2017; Whittington, 2016).

Foremost in this was a move towards a carer-centred focus, was giving carers *'parity of esteem'* alongside the adult with care and support needs. What this meant in practice was that carers were entitled to PBs if their needs met the national minimum threshold (eligibility criteria). The eligibility criteria are a three-step process, as defined in section 9 of the guidance (6.120 to 6.127), presented as a three-part list below, where carers must demonstrate:

1. That the care they are providing is "*necessary*". This is determined by whether the carer is providing care and support for needs the adult is capable of meeting themselves.
2. *"The carers health is deteriorating or is at risk of doing so* ***or*** [my emphasis] *is unable in one of more of the outcome areas"* (see table three on page 98 for a list of outcome areas).
3. As a result of one and two, the "*carer will have eligible needs if there is or there is likely to be a significant impact upon their wellbeing"* (*The Care Act*, 2014).

However, the ability of a legal framework to protect carers from the possible exclusionary nature of the role, identified in chapter three, deserves further critical examination; particularly, when consideration is given to the underlying assumptions and contradictory nature of the Act in the context of the political and economic climate in which it was conceived and enacted (Whittington, 2016). Furthermore, examining the assumptions behind PBs as a policy solution to the problem of caring is a key ingredient of being able to answer the first research question of identifying the intentions behind PBs as a policy solution to the problem of caring.

Before we move on to answer the first question, it is worthy of note that the Care Act (2014) was conceived at a time when Britain was entering a major economic recession, in 2008. Since then, reductions to LA budgets year on year have evidenced damaging effects on people with illnesses, disability, and their carers; the very people the Act was intended to support (Franklin, 2015; O’ Hara, 2014). One consequence of these LA reductions has seen families providing increasing amounts of care that many LAs can no longer afford to offer, which is highlighted in each ADASS annual budget survey produced since the Care Act (2014) was implemented in 2015.

Every year ADASS produces a Budget Survey. It is a unique insight into the health and wellbeing of Adult Social Care departments across England, based upon the views of their directors. The ADASS annual budget survey, in 2015/16, warned of the effects of five years of budget reductions, totalling £4.6billion, between 2010 and 2015, when the economic recession impacted Britain in 2008/9. In 2016/17, they estimated a further £0.5billion of cuts would have to be made, on top of the £4.6 billion savings made already (ADASS, 2017).

Directors surveyed in the 2016/17 financial year, suggested that the number of people receiving an adult social service had fallen between 2008/9 and 2016/17. Of those that did qualify for a social service in 2016/17, a significant number received less care than they would have before 2008 (ADASS, 2017). Their most recent 2020 budget report, published in July, showed the significant impact of COVID-19 on social- care provision. Their survey highlighted the significant concerns that directors had in meeting their statutory duties under the Care Act (2014), with only four percent confident their budgets would enable them to meet their care and support legal obligations. The authors warned, that without significant financial intervention from government, the lives of people who use social care and their family carers would be seriously impacted in terms of their lives and wellbeing.

This is really important context to bear in mind because it reinforces the findings from the genealogy of caring, that, the context of carers’ lives is more a determinant of their ability to participate in economic and social life, and the degree to which they can exercise choice, than a PB being able to promote social inclusion, choice, and control. If the person you care for receives less care than they did in previous years, then it is more likely that your caring role will increase to accommodate the gaps in provision.

Thus, reinforcing further, the need to scrutinise the claim the PBs can promote carer wellbeing. But, before moving on to carry out a WPR analysis of guidance in relation to the duties to assess, provide support, and promote the wellbeing of carers, it matters to outline why commentators expressed doubt that PBs given to carers may not promote choice and control in the way that policy suggested they could (Brooks *et al.*, 2017; Mitchell and Glendinning, 2017; Seddon and Robinson, 2015).

5.3 Personal budgets for carers

The assumption that PBs give carers choice and control follows the same logic it does for adults with care and support needs. The notion that theories of personalisation can be automatically translated for carers, in the same way that they are for adults with disabilities, is problematic, for two reasons. First, carers themselves have not formed a cohesive activist voice for change in the way that disabled people have (Clements, 2013). As discussed in the introductory chapter, disabled activist users of social care fought hard to have the same rights as non-disabled adults. Commentators like Clements (2013) suggest, that carers do not see themselves as a marginalised, or an oppressed, group in society, in the same manner that the disability movement does. Therefore, the idea that caring can be thought of as discriminatory in relation to, for example, equalities legislation, is not something that has gained a lot of traction in academic discourses. Hence, the paucity of evidence available that debates caring from a carer-led, activist movement perspective. A lack of identity with the term and social norms of care being a loving, dutiful act may contribute towards this lack of rights-based focus.

Second, as already mentioned, the premise of personalisation rests on the assumption that a PB increases the degree to which carers have choice and control over their lives, as a number of academic studies suggest they do (Jones *et al.*, 2014; Larkin, 2015; Moule *et al.*, 2014; Moran *et al.*, 2011; Woolham *et al.*, 2018). This assumption is blind to the economic and social context in which many carers provide care.

Personalisation, as a theory, relies upon a particular understanding and socially-produced form of knowledge that what it means and what it does is accepted as fact (Bacchi and Bonham, 2014). The logic of this argument suggests that PBs do facilitate choice and control through assessment and support-planning conversations. They do this because person-centred care, and support planning (a tenet of personalisation theory) puts carers front and centre of assessment conversations about the needs they have, and how a PB may be used in order to meet those needs. However, the idea that PBs give carers the ability to choose how public money is spent, in ways that best meet need, introduces two competing ideologies.

These two ideologies can best be described in relation to exercising rights in terms of inclusive citizenship, and active consumerism (Fitzsimons and Fuller, 2002; Lymbery, 2012; Rabiee, 2012). The idea, that PBs promote inclusive citizenship, rests on the assumption that PBs can act as a lever to promote a carer’s ability to participate in economic and social life, for example, that a PB should help facilitate the ability to balance a caring responsibility with a job or education. Inclusion is thought of, in this context, from a rights-based discourse. Such that, carers should not be denied the opportunity for social and cultural rights enjoyed by the non-caring population. Active consumerism, on the other hand, refers to the role of the market in shaping choice. Such that, carers are able to shop around for products and services from which to spend their PB budget on. It is this shopping-around element that produces the degree of choice. However, this premise rests on the assumption that a market of competing options is available from which a choice can freely be made. These two competing ideologies come up again in the WPR analysis of the guidance.

Before that analysis can happen, the reader must understand why WPR, as a method of policy analysis, was chosen, and the ontological and epistemological positioning that frames this approach.

5.4 Methodological approach – Rationale for the use of WPR as a method of policy analysis.

This first phase of the thesis aimed to answer the research question: *'What are the intentions behind PBs as a policy solution to the problem of caring?'* This lent itself well to a problem-questioning approach to policy analysis, which is provided by the WPR six-question model of policy analysis. The WPR approach views the policy-making process as a problem- creating, rather than a problem-solving, one (Bacchi, 1999; Bacchi, 2016; Shaw, 2010).

WPR, as an analytical approach, starts from the premise that policies produce, rather than solve, problems (Bacchi, 2016). This is because the meaning contained within the language of a policy affects what gets done and what does not. WPR begins with the solution to a problem, in the context of this thesis, the solution is the PB, and then the framework works backwards to explore how the solution is given meaning to solve the problem(s) that carers experience, i.e., poorer health and wellbeing outcomes, compared with the non-caring population, and greater difficulty participating in economic and social life compared with non-carers.

Thus, if the solution to the problems that carers face, such as an inability to maintain their own wellbeing (for example, balancing work with caring), then the problem is deemed to be inherently a problem for the individual carer to solve and manage. It is their lack of wellbeing that is the cause of the problem, and this can be remedied by the administration of a PB. The PB then becomes the lever that can restore the carer's wellbeing by facilitating their participation in economic and social life.

The focus using this problem-questioning approach becomes one of teasing out the problematic ways in which carers are represented within the guidance to the Care Act (2014). Bacchi (1999) refers to this as problematisation. How carers are problematised becomes an important task for the analyst. However, this first step assumes that the term 'problem' is commonly understood, and, like all concepts, that is often a misconception. Exploring the meaning of problem in the context of policy analysis, offers the reader greater insight into how the WPR approach is used to address the four questions posed in this chapter.

5.4.1 What is meant by the term problem?

As has been discussed already, the approach to policy analysis, adopted by WPR, draws from political discourse theory which takes a problem-driven as opposed to a theory- or method-driven approach (Glynos, 2007).

The starting premise of WPR, is that problems are not pre-existing states or conditions but that they are produced in policy proposals. That is, proposals about what to do have within them implicit problem representations or problematisations as they are referred to (Bacchi, 2016). The focus of discursive policy analysis is, therefore, on the social and epistemological conditions that lay the foundations of possibility for certain problematisations to emerge. The goal is to draw attention to *"the way we, under certain conditions, experience our 'problems' as well as our 'solutions' "* (Zwart, 2002, p. 39). This form of analysis enables the analyst to consider how epistemological and ontological assumptions shape our 'realities', and with what effects.

The concept of problematic situations is one that (Bacchi, 1999) associates with positivist and critical realist paradigms, where the focus lies in problems being accepted as something that lie outside of the policy process, waiting to be solved. Problems are viewed as exogenous to the analysis.

This positions problems as something that are produced (as particular kinds of problems) within the policy process itself. From this perspective, every policy solution contains an implicit representation of what the problem is represented to be, and, therefore, what needs to change. Thus, if it is the carer's lack of wellbeing that impedes their ability to manage a life of their own, alongside caring, then this is something that can be fixed. From this perspective, it is possible to improve someone's wellbeing by offering a PB.

Discussion of the problems associated with caring in policy documents are, in this context, not the product of neutral accounts of the effects of caring (from an empirical evidence base), but the result of judgements and choices that are made about how to present the problem of caring in a particular way. For instance, if they were neutral, evidenced-based accounts, then the policy response would acknowledge the empirical evidence of the disproportionate effects of caring being felt by some groups more than others. From this approach, we would see responses to carers on lower incomes, for example, being different from those on higher incomes, or a policy emphasis on female carer participation in economic life, because women carers are more likely to be out of work compared with male carers.

Before setting out the findings, from a WPR analysis of the Care Act (2014) guidance, the next section sets out the process taken that informed the data analysis.

5.5 Data Analysis

WPR provides the analytical framework upon which the language in the guidance is assessed. The WPR approach offers an analytical strategy for analysing governmental relations – with governmental understood in the expansive sense to incorporate a wide range of agencies, groups, and professionals.

The purpose of the WPR analysis of the Care Act (2014) guidance was three-fold. Firstly, to establish what the problem of caring was represented to be (WPR question one). Secondly to understand the assumptions that underpinned the way in which carers were represented (WPR question two), and, thirdly, to explore the silences and effects of these problem representations (WPR questions four and five).

The earlier genealogical analysis of caring addressed WPR question three, by reporting on the emergence of the term carer in policy and academic discourses and demonstrated the role of politics in the policy formation process.

A way into this analysis was established by reading the Care Act (2014) guidance sections, that related to the practices and processes involved in the administration of PBs for carers. These practices were: 1) Assessments of need; 2) Determination of eligibility for a PB (based upon the assessment outcomes); and 3) Support planning (agreeing in what way and how the PB will be administered e.g., as a DP, part DP, etc.).

These practices are defined in relation to duties and powers placed on public bodies (in this case the LA), as members of the public are owed what is known as ‘public law duties’, under social care statute law. These duties range from assessment, judgement-making as to the significance of need for the purposes of accessing adult social care, and appropriate care-planning arrangements. These duties must be delivered upon (Feldon, 2017).

In each of these practices, I identified how each section of the guidance identified what the problem of caring was represented to be, and, hence, its subsequent *"problem representation"* (Bacchi, 2016, p. 16). I wanted to examine, if the problem representation that it is a carer's lack of wellbeing which is what prevents them from being able to manage a life alongside caring.

While it was possible to deal with each of Bacchi's questions systematically, and address each one individually, under its own heading, an analytical decision was made to opt for what Bacchi describes as an *"integrated approach"* (Bacchi, 2009, p. 28). This is where questions are blended rather than dealt with sequentially. The benefit of blending the questions throughout the analysis meant that repetition was avoided. It also made for a more coherent narrative, in terms of illustrating the inter-dependency between the WPR questions. For instance, the section that analyses the way in which assessment practices problematise carers, also discusses the assumptions underpinning this problematisation, and refers to evidence from the genealogical analysis of caring to indicate how this representation came about, in order to demonstrate what is not discussed (WPR question four – what are the silences?) and the effects produced by this representation.

The analysis is structured in the following way:

1) Problematisations of assessment practices – duty to assess carers' needs
2) Problematisations of eligibility determination – duty to meet unmet eligible needs
3) Problematisations of support planning practices – duty to provide eligible carers with PBs.

5.6 Limitations of WPR as a method of policy analysis

WPR does not allow the analyst to examine the impact of a policy solution. The approach does not give the analyst any scope to assess how PBs, as a policy solution to the problem of caring, have worked in practice. Nor does it offer any scope to identify if people (who recognise they have a caring responsibility) relate to the way in which this mode of policy analyses suggests that carers are problematised by the Care Act (2014) guidance. Nor does this approach say anything about how carers themselves experience the PB process.

What is does offer, however, is an entry point into examining how policies directed to carers, that aim or claim to promote their wellbeing and participation in economic and social life through increased choice and control, become ways of governing carers (to draw from Foucault’s language) of policies as governmentality practices.

This first phase of the thesis seeks to examine how carers are spoken about as particular kinds of subjects within these specific practices of the guidance.

5.7 What is the problem (of caring) represented to be within the Care Act (2014) guidance?

This section sets out to analyse the way in which the guidance represents caring as a particular sort of problem, that can be resolved or eased through the administration of a PB. This is achieved by examining key elements of the guidance as they relate to the assessment and support planning duties and the overarching duty to promote the wellbeing of carers. The overarching duty, in this context, is used to mean that wellbeing is something that must be considered throughout the assessment and support planning processes, as well as a duty that applies to the council as a whole. The duty to promote the wellbeing of carers is not simply confined to the social services functions of a LA (*The Care Act*, 2014).

5.7.1 Problematisations of assessment practices

The Care Act (2014) guidance defines the assessment and eligibility process in sections 9-13 (6.1) as, *"one of the most important elements of the care and support system…the process must be person centred throughout, involving the person, and supporting them to have choice and control"*.

The assessment process is viewed as the front door to adult social care, for both carers and adults with care and support needs. *"The assessment process starts from when the LA begin to collect information about a person…***it should not be seen as gateway to care and support** [my emphasis] *but should be seen as a critical intervention in its own right which can help people to understand their situation and the needs they have, to reduce or delay the onset of greater needs[…]."* (Sections 9-13 (6.1)).

This introductory text, to the sections in the guidance that deals with assessment and eligibility, sets out a position where an assessment can be seen as an intervention in its own right, and may not always lead on to care and support in the form of a PB. The assumption being, that an assessment conversation may be an outcome in itself, if it leads to people (refers to both adults with care and support needs and carers) having a better understanding of their needs and know how, resultantly, to help themselves more.

The introductory passages to the guidance sections, on assessment and eligibility, go on to reflect both a responsibilising and individualising representation of the assessment process in the section that deals with the 'proportionality' of assessment processes. Proportionality refers to the assessment mode and describes a range of ways in which people can have their needs assessed, both in person, over the phone/online, or doing it themselves (referred to as supported self-assessment) sections 9-13. (6.3).

The concept of self-assessment is an interesting one, because it is one, *"where the person completes the assessment themselves and the LA assures itself that it is an accurate reflection of the person's needs"* sections 9-13 (6.3). This framing assumes both that people understand how to complete the assessment process and have some understanding of what it is they are being assessed against (eligibility criteria). It is not clear how a LA can assure itself that the needs identified in a self-assessment are an accurate reflection without meeting the person and carrying out their own assessment of needs. This is silent to the role that the LA plays in determining eligibility. It is not clear from the guidance how carers are informed of the eligibility criteria governing assessment outcomes This responsibilising effect is further evidenced in the sections of the guidance that deal with the purpose of the assessment process.

5.7.1.1 Purpose of the assessment process

"The purpose of the assessment process it to identify the person's needs and how they impact upon their wellbeing and the outcomes they wish to achieve in their day-to-day life." Sections 9-13 (6.9). The assessment also determines whether the identified needs are eligible for care and support and explore how care and support (in the form of PB) will help the person achieve their desired outcomes.

As part of this process, the LA, *"**must*** [my emphasis] *consider how the adult, their support network and the wider community can contribute towards meeting the outcomes the person wants to achieve"(6.10).*

The framing from the data extract above, implies that it is the responsibility on the person to look to themselves and their community for help and support, in meeting their needs, rather than to the LA. The emphasis given on *must* highlights that this practice is a statutory duty, meaning, it has been set out in an Act of Parliament, and is, therefore, a legal requirement. In other words, LAs have to explore ways the ‘wider community’ can support people to meet their own needs (the reference to person includes both adults with care and support needs and carers). The reference to wider community implicitly assumes the role of family carers as the person’s ‘support network’. This assumes a position and expectation that families will and can provide care with the reference to must, mandating LAs to ask families what they are able to provide in the way of care. Whether you want to work and care, or be able to have a full night’s sleep, the LA is duty bound to seek out ways to help you achieve these things without the intervention of a PB. It is silent to the gendered nature of the caring role and the fact that community, as discussed in the genealogy of caring, tends to mean care by women (Barnes, 2006; Dalley, 1996; Finch, 1983; Finch, 1989; Folbre and Nelson, 2000; Ungerson, 1997).

The reference to wider community and networks of support without explicit acknowledgement that this refers to family carers is contradictory because it does not acknowledge that networks of support (i.e., family carers) may have lives of their own, and assumes a willingness or ability to provide care. Of course, networks of support does not just refer to family carers, because there are those who rely on specific groups and organisations for care and support who do not have family and/or friends to rely upon. These contradictory framings can also be seen in the way that the adult assessment is framed as a carer-‘neutral’ process. Neutrality, in the context of the guidance, refers to the LA considering all of the adult’s care and support needs regardless of any support being provided by the carer. This position attempts to remove any assumption about a carer’s willingness and ability to provide care. Yet, section 10 (5), paragraph 6.10 implies the role of family from the reference to support network in contributing to outcomes: *“The assessment process also provides the opportunity for local authorities to take a holistic view of the person’s needs in the context of* *their wider support network. Local authorities must consider how the adult, their support network and the wider community can contribute towards meeting the outcomes the person wants to achieve."*(Statutory Guidance, Care Act, 2014).

The responsibilising effect on the individual to look to themselves and their community, first, for help and support, rather than the public body (LA), mirrors the discursive historical analysis of caring provided in Chapter Four. We saw the construction of the term carer in 1990, with the introduction of the NHSCCA being synonymous with community care, representing care by families and informal networks, and, therefore, care by women.

This framing on the role of the adult's own *"support network"* and *"wider community"*, silences the disproportionate effect that caring responsibilities have on women, as has been illustrated in the introductory chapter of this thesis. More broadly, it silences any debate about the impact of caring on the adult's support network and wider community. What is meant by that, is, that there is no acknowledgement (as demonstrated in the genealogical analysis of caring) that caring is a social determinant of health and wellbeing. The ability of families to provide care is shaped by a host of factors including socio-economic and demographic characteristics.

What this contradictory positioning demonstrates is the complementary tension that exists for LAs, on the one hand, supporting carers to promote their own wellbeing and recognising their need for economic and social participation, at the same time, relying significantly on the family's contribution towards the provision of care as a free source of labour. This jarring occurs throughout the guidance in relation to, and, in particular, the guidance as it relates specifically to the carers' assessment process.

5.7.1.2 The duty to assess carers' needs

The duty to offer a carer's assessment is based on*, "where an individual provides or intends to provide care for another adult, and it appears that the carer may have* ***any*** [my emphasis] *level of need for support the LA* ***must*** [my emphasis] *carry out a carers assessment."* Sections 9-13 (6.61).

The guidance goes on to state that the assessment must consider the outcomes the carer wishes to achieve in their daily life, and, *"beyond"* (6.19) their caring responsibilities and the impact of caring upon their ability to do the things that they wish. *"This includes considering the impact of caring responsibilities on a carer's desire and ability to work and to partake in education, training or recreation activities such as having time to themselves."* (6.19). This represents caring as something that should not deny a person from having a life of their own. The emphasis on the word desire, in relation to accessing employment, also implies that if a carer is not working then whether or not they wish to work should be something considered by the assessing practitioner. This implies that the assessment should look at the needs of the carer as both a person and as a carer.

This idea, of looking at the needs of the carer as a person, first (for example, aspirations about career and their own future), ties in with the neutrality of the adult's assessment process, as described in section 5.7.1. above, on the purpose of the assessment process. Thus, if the adult assessment determines eligibility, ignoring what the carer is able to supply, then, logically, it follows that the support planning processes (the point at which the carer's contribution is agreed and decided) should, in theory, have determined what outcomes the carer wants to achieve; particularly if a combined assessment has been carried out, where the needs of the carer and adult, with care needs, are assessed together. This is emphasised further in paragraph (6.65), which talks about the requirement to take a *'whole family approach'* to assessment under the Care Act (2014). The intention being, for the LA to consider the needs of the family, in the round, moving away from individual and separate assessments of need that take no account of the relationality that may exist between the carer and the person they care for. The guidance makes specific reference to this as a way to cut down on the time of completing two separate assessments: *"This will avoid the LA carrying out two separate assessments when the two are intrinsically linked"* (6.74).

The focus on assessment being person-centred and needs-based, is to shake out the culture of assessing for particular services, such as respite, day care- and home-care services, as has been discussed in the genealogy of caring; these service-led models became seen as paternalistic and oppressive, as a professionally led rather than being a person led-process.

The person-centred nature of the assessment process can be seen in the strengths-based language used in the guidance to denote a capabilities approach. *"At the same time as carrying out the assessment the LA must consider what else (other than the provision of care and support) might assist the person in meeting the outcomes they want to achieve…the LA should consider the person's strengths and capabilities and what support might be available from their wider support network"* (6.63).

The reference to people's strengths and capabilities places the emphasis on the individual to come up with the solutions to the problems of their lives, rather than the onus being on the LA, as a public body, to find solutions, such as sufficient social care support to the adult with care needs, such that the carers can reduce the amount of care they provide. Again, we see in the use of this language a responsibilising effect, which is silent to the impact of significant under investment and cuts to adult social care budgets, evidenced by successive ADASS reports in the previous chapter.

However, the strengths-based, person-centred approach to the language used in the guidance is a far cry from the deficits-based language used in the eligibility guidance, which very much creates an impression that LAs are really assessing for deficit, as people are required to say what they are unable to achieve, in terms of outcomes, in order to qualify for a PB.

5.7.2 Problematisations of eligibility determinations

The national eligibility criteria set out a minimum threshold for carer support needs, which the LA must meet, sections 9-13 (6.100). The threshold is based upon the impact a carer's needs for support has on their wellbeing. This is a three-step process, as follows:

1. *"Care must be necessary – if the carer is providing care and support for needs the adult is capable of meeting themselves, the carer may not be providing necessary care" (6.124).*
2. *"The second condition that authorities must consider is whether the carer's physical or mental health is either deteriorating or is at risk of doing so." (6.125)*
3. *"Or the carer is unable to achieve one of more outcomes without assistance." (6.126)*

Outcomes are defined in relation to a series of social indicators, as shown in table two on page 97. Table two shows how the outcomes are already predefined as a series of activities of daily living. This contradicts the strengths-based, person-centred assessment process, where the carer themselves chooses the outcomes that matter most to them. Although the guidance is clear, not to treat the outcomes or wellbeing areas as an exhaustive list.

Condition one of the eligibility criteria and the provision of necessary care, assumes that being able to define and agree this with carers is a clear-cut process. It leaves open a question mark about whose decision and judgement it is, that the carer is providing support that is not necessary, because the person being looked after is capable of meeting their own needs.

Being *"unable to achieve one or more outcomes without assistance"* (6.126) is defined as meaning you are unable to, for example, *"[…] carry out any caring responsibility for a child"* (outcome a), because you rely on someone else (without assistance) to, for instance, take your children to school in the morning because you have to provide care for another adult.

Eligibility for a PB turns on there being a significant impact upon a person's wellbeing because of an inability to achieve one of more of the prescribed outcomes. We can see from the wellbeing list in table two below, that the concept is conceived of as a series of indicators that comprise a carer's wellbeing. Again, the guidance is clear to state that this is not to be viewed as an exhaustive list. This assumes that the indicators that are thought to comprise wellbeing are commonly accepted, as such, and that the concept holds meaning for carers in the way that it does for LAs. This is silent to the subjective meaning that wellbeing may hold for carers. The effect of this indicator list is that is puts a spotlight on individual wellbeing, as if these factors, alone, are the only characteristics that contribute to a carer's wellbeing, which takes no account of personal circumstances and carer's ability to affect their own wellbeing. Because of the significance that wellbeing plays within the guidance, both as a whole council duty and the fact that eligibility for a PB rests on a judgement that caring is having a significant impact upon a carers' wellbeing, an analytical decision was taken to subject the concept to further scrutiny, using the WPR six-question model.

The reference above, to significant impact on wellbeing not being defined by the Care Act (2014) regulations, and *"therefore must be understood to have its everyday meaning"*(6.131), suggests an inference that *"every day meaning"* may be both an objectively- and subjectively led process, because LAs must consider the significance of the impact of a caring role from the carer's point of view *"…on their daily lives, their independence and their own wellbeing."* (6.131).

Once significance of impact on wellbeing has been established, then a carer is eligible to receive a PB. The next section outlines the way in which caring is problematised within the guidance on PBs, the assumptions, silences, and effects.

Table 2. Carer Eligibility Criteria [© The Care Act (2014)]

Needs	The needs arise as a consequence of providing **necessary** care to an adult, and the carer is unable to achieve the following:
Outcomes	**Wellbeing**
The carer’s physical or mental health is, or is at risk of, deteriorating, **or**	As a consequence, there is or is likely to be a **significant impact** on the carer’s wellbeing, including:
As a result of the carer’s needs, the carer is **unable** to achieve **any** of the following outcomes:	a) Personal dignity (including treatment of the individual with respect)
a) Carrying out any caring responsibilities the carer has for a child	b) Physical and mental health and emotional well being
b) Providing care to other persons for whom the carer provides care	c) Protection from abuse and neglect
c) Maintaining a habitable home environment in the carer’s home (whether or not this is also the home of the adult needing care)	d) Control by the individual over day-to-day life (including, over support provided, and the way it is provided)
d) Managing and maintaining nutrition	e) Participation in work, education, training, or recreation
e) Developing and maintaining family or other significant personal relationships	f) Social and economic wellbeing
f) Engaging in work, training, education, or volunteering	g) Domestic, family, and personal relationships
g) Making use of necessary facilities or services in the local community, including recreational facilities or services	h) Suitability of living accommodation
h) Engaging in recreational activities	i) The individual’s contribution to society
A carer is regarded as being unable to achieve an outcome when s/he:	
a) Is unable to achieve it without assistance.	
b) Is able to achieve it without assistance but doing so causes the carer significant pain, distress, or anxiety.	
c) Is able to achieve it without assistance but doing so endangers, or is likely to endanger, the health or safety of the carer, or of others.	
From the guidance 6.130. *“The term ‘significant’ is not defined by the Regulations and must therefore be understood to have its everyday meaning. Local authorities will have to consider whether the carer’s needs and their inability to achieve the outcomes will have an important, consequential effect on their daily lives, their independence, and their own wellbeing”.* **6.131.** *“In making this judgment, local authorities should look to understand the carer’s needs in the context of what is important to them. The impact of needs may affect different carers differently, because what is important to the individual’s wellbeing may not be the same in all cases. Circumstances, which create a significant impact on the wellbeing of one individual, may not have the same effect on another. “*	

5.7.3 Problematisations of support planning practices

The guidance begins by asserting the purpose and aims of the carers PB in section 26 (11.40):

> *"The carers personal budget must be an amount that enables the carer to meet their needs to continue to fulfil their caring role and takes into account the outcomes that the carer wishes to achieve in their day-to-day life. This includes their wishes and/or aspirations concerning paid employment, education, training, or recreation* ***if*** [guidance emphasis] *the provision of support can contribute to the achievement of these outcomes"* (*The Care Act*, 2014).

The problem of caring is represented to be a problem for the individual carer to solve. This can be seen in the way that the discourse frames a budget as its primary objective is to support the carer to *"[…] continue to fulfil their caring role […]"* (11.40) The presumption with this framing is that the PB prioritises the sustainability of the caring role, first, before its ability to facilitate the carer's wishes and aspirations for their own lives are considered. The inclusion of the word *if* in bold and italicised, is interesting, because it casts doubt on the ability of PBs to be able to support carers to achieve outcomes in relation to employment, education, and leisure. This is further echoed in paragraph 11.41 that states:

> *"LA must have regard to the wellbeing principle as it may be the case that the carer needs a break from caring to look after their physical/emotional,* **social and economic wellbeing** [my emphasis] *and to spend time with family and friends. Whether or not there is a need for replacement care, carers may need support to help them to look after their own wellbeing. This may be:*

- *A course of relaxation classes*
- *Training on stress management*
- *Gym or leisure centre membership*
- *Adult learning*

- *Development of new work skills or refreshing existing ones (so they* ***might*** [my emphasis] *be able to stay in paid employment alongside caring or take up return to paid employment)*
- *Pursuit of hobbies, for example, purchase of garden shed or laptop" (The Care Act, 2014).*

Examples like those above create a link between stress and internal deficit, where a PB is positioned as fix which can build internal strength and individual coping strategies. This responsibilising framing is silent to the structural inequalities that show that some groups of carers are disproportionately affected by the negative effects of caring more than others, which has been discussed already in earlier chapters.

The examples from the guidance shown above assume an association between stress management, or relaxation, and positive wellbeing. It creates the idea that responsibility lies with the carer for the fact they may be overwhelmed or overburdened by their role, which may be solved by training on stress management rather than reducing the amount of care they may be providing, so that they are able to return to paid employment or be able to enjoy better health. It also implies it is the carer's responsibility to change, for instance, their mind-set, via a course on relaxation or stress management, or to make productive use of their free time, through hobbies. It creates a link between stress and the individual carer who has the control to reframe how they think about their caring role.

The effect of this is that it shifts responsibility away from the LA and society more broadly, for the adverse effects of caring, and is silent to the disproportionate effects of gender and socio-economic status. More broadly, it is silent to what else could change in order to improve the wellbeing of carers' lives, for example, a well-funded – social care system, or, more fundamentally, change in terms of making caring more of a shared responsibility between men and women, the state, and families.

The focus on individual self-reliance, such as taking out a gym membership to improve your own wellbeing, also creates a culture of blame, because it implies that if you do not spend your PB on something that will improve an area of your wellbeing, then you may be thought of as an irresponsible carer. It creates subject positions that divide carers into responsible and irresponsible subject positions. This dividing practice has the effect of not only responsibilising carers for the provision of care, but, also, creates the impression that the government can no longer be relied upon to support adults with social care needs. It silences the experience of those carers who are unable to maintain their own wellbeing, because of a range of personal circumstances that may be beyond the individual's control. It silences alternative framings of care-giving that could be considered exclusionary and discriminatory, such as feminist critiques of care and political theories of care. It encourages individual carers to look within to solve the problems they face with caring, rather than to question dominant neoliberal values of care that were discussed in earlier chapters, and how caring can be seen as social determinant of health, rather than an individual responsibility.

The focus on individual wellbeing is worthy of greater scrutiny within the guidance of the Care Act (2014), because of the centrality of its positioning as the determining factor that leads to a PB, but, also, because the duty to promote wellbeing is something that LAs must consider throughout the assessment and support- planning functions, as well as the activities of the LA as a whole. The next section offers a detailed analysis of wellbeing, using the WPR method to understand how wellbeing has been problematised as an individual responsibility, by looking back at its discursive history and silencing effects that come from this framing in policy discourses.

5.8 What is the problem of wellbeing represented to be?

Section 1 (1) of the Care Act states: *"Local Authorities must promote wellbeing when carrying out any of their care and support functions. Wellbeing is a broad concept and is defined as it relates to:*

a) Personal dignity (including treatment of the individual with respect)
b) Physical and mental health and emotional wellbeing
c) Protection from abuse and neglect
d) Control over day-to-day life (including over support provided and the way it is provided)
e) Participation in work, education, training, or recreation
f) Social and economic wellbeing
g) Domestic, family, and personal relationships
h) Suitability of living accommodation
i) The individual's contribution to society"

(*The Care Act*, 2014)

The assumption underlying this construction of wellbeing is that it exists in two dimensions, objective and subjective. The objective elements are thought about in relation to how it can be measured, because it is based on assumptions about basic human needs and rights expressed through a broad range of indicators, as described in the list above. Objective wellbeing could, therefore, be measured through self-reports, for example, asking carers how caring affects their health or ability to access the labour market But it is also expressed in relation to being or feeling, with its reference to a) personal dignity, and d) control over life, which suggests that wellbeing can also be about feeling good and comprising an individual's experience of their life.

The problem representation in this description is that wellbeing is viewed as an essential state. It creates the idea that improved levels of wellbeing are indicators of good health. It also implies that wellbeing can be measured, yet the Care Act (2014) offers no guidance on how these individual characteristics of wellbeing should be measured nor indeed, what is meant by each indicator. For instance, it is difficult to see how a social worker could assess the extent to which a carer's dignity, or contribution to society, is affected by their caring role without a working definition of what is meant by these terms.

Moreover, the threshold for determining eligibility for a PB is based upon there being a significant impact upon the carer's wellbeing (the indicators outlined above). But, the Act does not define significant, instead, it suggests it *"must therefore be understood to have its everyday meaning"* section 1 (6.130). *"In making this judgement, LAs should look to understand the carers needs in the context of what is important to them. The impact of needs may affect different carers differently because what is important to the individual's wellbeing may not be the same in all cases"* (6.131). This implies that eligibility determination is both an objective and subjective phenomenon because the assessor must take into consideration what matters to the individual.

The Act, in this context, takes an individualistic approach to defining wellbeing as something you can acquire. If you have good health, a job, relationships, and feel valued, then you will have good wellbeing. What it does not do, however, is to consider what wellbeing means to the individual (if indeed it does mean something); or offer any guidance to practitioners how they are, in any practical sense, able to measure a carer's wellbeing. Furthermore, embracing the idea of wellbeing, as something that is externally observable, masks the effects of structural inequality on carers' lives, and is silent to the unequal way in which people with caring responsibilities experience their caring roles.

It has already been established in earlier chapters of this thesis, that people who are more likely to take on caring roles are those who are already struggling in precarious employment, or are unemployed, and when they do, are, also, more likely to find themselves in more intense caring roles compared with carers in secure, well-paid jobs (Al-Janabi *et al.*, 2018; Carmichael and Ercolani, 2016; Verbakel *et al.*, 2017). Evidence presented in Chapter One indicates that characteristics, such as gender, class, and income are important determinants of a carer's ability to participate in economic and social life. This reflects caring as a social determinants of health. (Arber and Ginn, 1992; Dahlberg and McKee, 2016).

What can be taken from the discussion thus far, is the problematic nature of conceptualising wellbeing as an observable and measurable state, that can be thought about in relation to a series of indicators. This does not capture the subjective knowledge of what wellbeing may mean to the individual. It is also important to understand how this conceptualisation of wellbeing came about, because it is fundamental to the way in which people access adult social care in England. Exploring the rise of wellbeing in public and political discourse will help us to understand this; and it is where we turn to next.

5.8.1 How has this representation of wellbeing come about?

Different philosophical debates frame different perspectives on what wellbeing is, how you define, describe, measure, and quantify it (Bache and Reardon, 2013; Bache *et al.*, 2016; Scott, 2012).

These 'conceptions' of wellbeing centre around whether it is defined and explored at the individual, government, or societal level (Bache and Reardon, 2013; Scott, 2012).

It is possible to go as far back as Aristotle, who described 'eudaimonia' as an overall state of human flourishing, that can be achieved through a process of ‘living’, ‘doing’, and ‘being’. Bache *et al.* (2016) suggest that this Aristotelian approach is still in evidence today, in much of the 'capabilities' policy discourse which centres on ideas that people should be able to fulfil their own potential, find meaning and purpose, to have a happy and fulfilled life. This capabilities approach has also been identified in the assessment guidance accompanying the Care Act (2014).

Systems, such as education and health, are cited as examples of institutions that can support people to become 'capable'. This conception of wellbeing gives an indication of the role of government in meeting these needs. This certainly resonates with the discourse within the Care Act (2014), which talks about the purpose of the assessment and support planning process to enable carers to realise their own potential, and *“[…] assessments must consider the outcomes that the carer wants to achieve in their daily life, their activities beyond their caring responsibilities”* section 9, (6.19). In summary, this approach suggests that wellbeing is considered as a state (physical and mental). What is less clear, is whether a state of wellbeing is attainable through a course of action, behaviour, or thought pattern; or indeed if wellbeing is a state which carers aspire to.

Certainly, from the discourse analysis presented thus far, in relation to the assessment and PB guidance, it would imply that wellbeing is both a physical and mental state, attainable through individual action and personal responsibility. This has been demonstrated by the way in which examples of what a PB can be spent on are framed, as products that improve resilience and coping strategies, such as a course on complementary therapies, or counselling.

Improved levels of wellbeing are, therefore, assumed to be related to improved levels of health. Traditional public health approaches have focused upon healthy behaviours and lifestyles to promote good health and wellbeing. The aim being, to encourage people, considered to have lower levels of wellbeing and health, to change their lifestyles and, therefore, improve their health. People are viewed as the units of change, in charge of increasing their own wellbeing, which assumes that they have the control and responsibility to improve their own state of health.

A pattern is emerging, both within the Care Act guidance and the wellbeing discourse, that frames the problem at the micro-individual level, which takes no account of the way in which the macro environment may contribute towards the problems associated with wellbeing. This speaks to neoliberal models of welfare, discussed in the discursive history of caring in Chapter Two. Self-reliance endorses neoliberal thinking of the individual autonomous subject, able to self-govern and responsible for their own wellbeing and happiness. Within this model, carers have agency to choose how they spend their PB. However, within this neoliberal paradigm is the unwritten condition that you spend it responsibly in ways that make you a better, more-productive carer.

Getting people to take responsibility for improving their own wellbeing can be seen in the way that PBs for carers are framed as enablers of choice and control: choice, in being able to shop around for things to buy with your PB, that will improve your emotional health, such as stress management, or pampering days, and control because the individual carer has a greater say in defining their own needs and how best they can be met.

Self-reliance has fuelled a self-help industry for carers, with Carers Centres offering activities that carers can spend their PBs on, such as short breaks or pampering days. Yet, once this break or pampering session has occurred, then carers return to their caring responsibilities that may be, in part, the source of the stress and anxiety that necessitated a pampering day in the first place.

This begs the question; who is responsible for achieving a state of wellbeing? Despite carers being owed public law duties, in the form of assessment and support, from the evidence presented so far, it is clear that it is the individual carer's responsibility to promote and maintain their own wellbeing. The notion of choice and control in the form of PB, therefore, becomes an illusionary choice, because the empirical evidence points to the circumstances of carers lives being a stronger determinant of the extent to which they have choice and control over their lives. The illusion of a PB acting as a lever that provides choice speaks to theories of empowerment (as discussed in Chapter One). The more self-empowered you feel, the greater your wellbeing. This rationale provides a legitimacy for government to push a self-reliance wellbeing agenda onto carers, because it removes responsibility and cost for the provision of care away from them.

But others suggest that wellbeing is made up of much more than individual lifestyle factors alone. If we look to the literature on the social determinants of health for, example, we start to see how wellbeing is framed at a societal level. Marmot and Wilkinson (2006) suggest that increased wellbeing can be achieved through the narrowing of the wealth and health gap, between the richest and poorest people in any society. By making societies more equal, this will reduce the health and social inequalities that occur; though critiques of Marmot and Wilkinson (Forbes, 2001) suggest that they are blind to the relationship between health and social class, because they focus purely on the income gap between rich and poor. The idea is, that the conditions (economic, environmental, and social) into which people are born directly influence the health they will experience. This positioning suggests that responsibility lies beyond individual authority. Wellbeing itself may be beyond the control of the individual to 'attain' through their own thoughts or actions.

What this discourse, perhaps does not account for, is the inherently subjective nature of health and wellbeing as both a physical and emotional state. People may well for, example, take part in so called ‘risky lifestyles’, such as drinking beyond the recommended weekly alcohol intake, or smoke cigarettes, and suggest that this contributes positively towards their wellbeing (feeling good) and health. Others may prefer their own company, and not consider or define themselves as being lonely in their own terms, despite research evidence pointing to the risks of isolation to health (Walker and John, 2012). The idea that an absence of something denotes poor wellbeing is not always the case. Many people may actively choose not to work, and that may indeed contribute positively towards how they feel. Indeed, if a lack of employment is one of the factors that contributes towards poor wellbeing, then, arguably, this is something that the Care Act (2014) should be addressing more vociferously for carer, as we have established that many people are unable to work because of their caring responsibility, and this can have a significant impact upon their financial wellbeing.

This raises another important question, over whether wellbeing is a subjective or objective *state,* a *process,* or an *outcome* (an end in itself), or something that is necessary to achieve another outcome For example, is it important to have a positive state of wellbeing to be a ‘good enough’ carer or someone’s parent? Is wellbeing a static state, or one which shifts over time, both within individuals and across individuals? Does, for example, the wellbeing of carers change with the ageing process or income level? What underpins these questions is the evidence that points to the variation that exists within and between carers, according to longitudinal research (Al-Janabi *et al.*, 2018; Carmichael and Ercolani, 2016; Verbakel *et al.*, 2017). It has been established in the thesis, already, that income and social class are important determinants of a carers wellbeing, in terms of being able to participate in economic and social life; yet there is nothing in the Care Act (2014) that talks about the heterogeneity of caring, and the disproportionate effects being felt more by carers at the lower end of the socio-economic spectrum.

Thinking about wellbeing as a dynamic state opens up the possibility to identify a relationship between socioeconomic and environmental (structural) conditions, that contribute towards wellbeing and health. It may not simply be the product of constituent parts or social indicators, but a much more complex interplay between biology, income, social class, and the way in which society constructs itself (politically and economically) that can impact upon a carers health and wellbeing (Blas *et al.*, 2010). This framing of health and wellbeing being, socially determined, has shifted understandings of health beyond the absence of disease (Marmot and Wilkinson, 2006).

5.9 Summary

This chapter has carried out a WPR analysis of the Care Act guidance in relation to practices associated with PBs, these were: 1) Assessment practice; 2) eligibility determination practices; 3) support planning practices; and 4) the duty to promote wellbeing. It examined two key discourses within the guidance of the Act – how the problem of caring was represented, and how the problem of wellbeing was represented, followed by an exploration of the assumptions, silences, and effects brought about each of these problem representations. Findings from the discursive analysis found that the guidance reflected a responsibilising agenda. Both caring and wellbeing are framed as an individual responsibility for the carer to manage. Family responsibility for the provision of care can be seen throughout the assessment and support planning practices, with reference to the role of the family in supporting the adult with care needs, and in the ways that the guidance describes how carers can spend their PBs, on ways that improve their individual wellbeing and coping strategies.

Phase one of the study asked: *'What are the intentions behind PBs as a policy solution to the problem of caring?'* The answer to this question is that the guidance accompanying the Act would imply that the intentions are to give carers equal access to assessments and support, in the same way that adults have (referred to as "parity of esteem") to increase the choice and control they can exercise over their lives, through outcomes-focused, person-centred assessment and support planning processes, and third, to promote their wellbeing (encompassing participation and inclusion) through PBs.

However, a WPR analysis shows that the intentions of the Care Act (2014) guidance are to responsibilise carers, both for the provision of care and their own wellbeing. This is evident by the ways in which the guidance suggests that PBs can be spent on activities that develop the skill, knowledge, and coping strategies of people with caring responsibilities. Another intention behind carers PBs is to shift responsibility for the provision of care away from government. The more that families provide care, the less government is required to.

As mentioned in the methods section of this chapter, one of the limitations of the WPR approach is that it does not offer the analyst the opportunity to examine the outcome of policy solutions. Therefore, examining what happened in England, after the introduction of PBs for carers, would open up the possibility to explore if more carers received outcomes focused assessments and PBs since 2014, and, indeed, if PBs are associated with promoting carer wellbeing as has been suggested by the policy guidance.

In the next chapter, phase two of this thesis carries out a quantitative analysis of the Care Act (2014) guidance on carer wellbeing, to see if the policy solution has had the intended effect that the guidance suggests it would.

Chapter 6 – Phase two - Impact of the Care Act (2014) on Carer Wellbeing: A Quantitative Study

6.1 Introduction

Phase two of this thesis now moves on to assess whether the policy intention that PBs can promote carer wellbeing were realised, in practice, by conducting a quantitative secondary analysis of carer-specific performance and survey (cross sectional) data to answer the research question aligned with this phase of the thesis: *'Do PBs promote carer subjective wellbeing across England'*?

Given that one of the intentions of the Care Act (2014) was to promote the wellbeing of carers, and key to that being achieved was through the provision of PBs, this phase of the thesis sought to examine whether those intentions were evidenced in practice across England.

Three data sources were identified as the most appropriate in being able to address the research question. These data sources are outlined briefly now in this introductory section, so that readers can understand the rationale for their choice in addressing the research question, and also how hypotheses were formed based upon PBs providing a policy solution to the problems that carers face. The overview of data sets in the next section also includes a description of the relationships between them. This is because each data set is inter-related. Measures from one data source are used to populate measures in another.

Data were sought that would identify how many carers were being assessed and supported via PBs since the introduction of the Care Act (2014). These data were located in the annual performance data CASSRs must collect on the number of adults who receive assessment and support from them, called Short- and Long-Term Returns (SALT). The carer elements of these data were used to describe how many carers were receiving an assessment of need and the mode of administration of a PB between 2014 and 2020. It would be anticipated that the new duty to offer carers an assessment based on the appearance of need (under the Care Act

(2014), would lead to an increase in the number of carers being assessed since the implementation of the Act. This is because assessment is the gateway to identifying eligible need, and sections 9 to 13 of the Statutory Guidance, paragraph (6.120) states that *"carers can be eligible for support in their own right".* The Eligibility Regulations set out a range of outcomes (see table two in chapter five above) that LAs must consider whether the carer is able to achieve. Paragraph (6.12) of the Statutory Guidance states: *"The carer will have eligible needs met if they are unable to achieve any of these outcomes and as a result there is, or is likely to be, a significant impact on their wellbeing".* As has been demonstrated earlier in Chapter One of this thesis, the new assessment criteria were viewed by the sector as a much more inclusive definition of entitlement to assessment, and therefore, were considered likely to bring more carers into the system for assessment, because the onus (introduced by the Care Act) was now on the practitioner to offer assessment rather than simply inform carers of their right to one that existed in earlier carer statute (Carers (Recognitions and Services) Act 1995) (ADASS, 2016, 2018). These data were used for descriptive analysis only and led to the following testable hypothesis:

- Hypothesis 1 – SALT data returns will show an increase in the number of carers receiving assessment and support in the form of a PB between 2014 and 2020.

The second data source used for analysis purposes was the Adult Social Outcomes Framework (ASCOF). These data were included because they measured how well care and support services achieved the outcomes that mattered most to people, as defined by findings from the biennial Survey of Adult Carers in England (SACE).

It was plausible to hypothesise that carer satisfaction with social services would have improved since the introduction of the Care Act, because theories of personalisation suggest that person-centred support via PBs increases choice, control, and therefore may lead to increased feelings of satisfaction (Jones *et al.*, 2014; Larkin, 2015; Moran *et al.*, 2011; Moule *et al.*, 2014; Woolham *et al.*, 2018).

ASCOF are both performance- and survey-level data collected annually by CASSRs. The carer-specific performance elements of the ASCOF data are populated with data from the SALT. These indicate the number of carers who have received an assessment of need and support by CASSRs.

Carer-specific outcomes chosen for descriptive analysis (from the ASCOF) were carer reported, quality-of-life scores (QoL); carer satisfaction with social services, and the extent to which carers reported they were involved and consulted in discussions and decisions about the cared for. The remaining outcome measures related to the cared-for person and were therefore excluded from this analysis. This led to three further testable hypotheses:

- Hypothesis 2 - Carers will report increases in their QoL scores between 2012 and 2019.[1]
- Hypothesis 3 – Carers will report increases in their satisfaction with Social Services between 2012 and 2019.
- Hypothesis 4 – Carers will report improvements in their involvement and consultation in discussions and decisions about the cared for between 2012 and 2019.

The third and final data source included in this secondary analysis was the Survey of Adult Carers in England (SACE). The SACE is a biennial survey sent out to a representative; randomly selected sample of adult carers known to CASSRs in England. It began in 2012, and findings are used to monitor the impact of CASSRs services to carers. It is also used to populate a number of the measures contained within the ASCOF data. For example, questions

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[1] 2012 is chosen as the start date for all ASCOF outcome measures as this represents the first SACE survey data collection period.

from the SACE are used to create the ASCOF quality of life (QoL) measure – see methods section below for details on how ASCOF survey methodologists constructed a valid and reliable measure of QoL.

SACE survey questions that aligned with indicators of wellbeing were used in this thesis to create a wellbeing outcome variable, in order to carry out a linear regression analysis, to identify whether a statistically significant association existed between moving from not having a PB to having a PB, and its effect on wellbeing as an outcome variable. The methods section below (section 6.2) outlines the methodological process involved in creating this continuous outcome variable. Given the aforementioned discussion and intention of PBs, as a policy solution to the problems that carers face, it was plausible to hypothesise that having a PB may lead to improvements in carer reported wellbeing scores. This led to the following final testable hypothesis.

- Hypothesis 5 - Having a PB improves carer –subjective, wellbeing scores.

Table three on the next page shows a breakdown of each data set with its corresponding hypothesis and mode of analysis used in order to prove, or disprove, the aforementioned hypotheses.

Table 3 Data sets used in this thesis

DATA SET	TYPE OF ANALYSIS	SAMPLE SIZE	VARIABLE TYPE	HYPOTHESES
SALT	Descriptive – measures of central tendency	2018/19 survey year N=292,360, n=136,095[2]	1. Number of carers receiving assessment. 2. PB administration modes	1. Increase in the number of carers receiving assessment and support in the form of a PB between 2014 and 2020.
ASCOF	Descriptive – measures of central tendency	2018/19 survey year N=292,360, n=136,095[3]	1. Carer QoL score 2. Carer satisfaction with Social Services scale 3. Carers included in discussions or decisions about the cared-for scale.	2. Carer reported increases in QoL scores between 2012 and 2019. 3. Carer reported increases in satisfaction with Social Services between 2012 and 2019. 4. Carer reported improvements in involvement in discussions & decisions about the cared-for between 2012 and 2019.
SACE	Inferential – Linear regression	2018/19 survey year N=292,360, n=136,095	Independent (all dichotomous) variables – PB, gender, age & ethnicity. Dependent (continuous variable) – wellbeing scale	5. Having a PB increases carers' subjective wellbeing scores between 2014 and 2020.

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[2] ACOF and SACE samples are identical. The survey elements of the ASCOF are taken from sample respondents to the SACE survey.
[3] ACOF and SACE samples are identical. The survey elements of the ASCOF are taken from sample respondents to the SACE survey.

6.2 Methods

6.2.1 SALT data

> Short- and Long-Term Returns (SALT) data are performance level data collected annually by NHS Digital from 152 English CASSRs. They are aggregate data relating to the activity of Councils. SALT reports on the number of carers who have been assessed and supported in any one year (support is defined in relation to four modes in which a PB can be administered).

Data gives government and CASSRs an assessment of performance at both local and national level.

SALT data were used in this analysis for descriptive purposes only. They showed whether or not the numbers of carers being assessed by CASSRs had increased since the introduction of the Care Act (2014).

Data from the SALT collection are used by NHS Digital (who curate and administer the data) to create a number of the measures in the ASCOF. For example, SALT data on the number of carers assessed and supported by CASSRs populates measure 1C in the ASCOF data set (*'proportion of users and carers receiving self-directed support (SDS) and SDS via a DP'*). Self-directed supported is a term used to describe a PB. Where the user directs and manages their own care and support arrangements.

6.2.2 Variables chosen for descriptive analysis

Variables were chosen that would enable me to describe the frequency and distribution of carers being assessed and supported between 2014 and 2020. These were aggregate (counts of carers, and events). Events were defined as the type of support being received by the carer and are outlined below. The carer-support elements of the data capture the number of carers who have had a carers assessment or review during a financial year. In the SALT data, these are recorded by the age group of the carer and the condition of the person they are caring for. The age of the carer and condition of the person being look after were not included variables for the analysis, because I wanted to know how many carers (as a population group) were receiving assessment and support, not whether there were differences in who received an assessment of need and support because of the age of the carer or nature of their caring role. The SALT data also captured the different types of support provided to carers (PB modes of administration) as an outcome of their assessment or review.

PB mode of administration is categorised as follows:

1. Direct payment only – Where the carer has made an informed decision that they want to be responsible for purchasing services for themselves under direct contracts with providers, to which they will be the formal party.

2. Part direct payment – Where the carer decides to take some of the PB allocations as DP and some as a managed PB (where the LA arranges and manages the service between the carer and provider, for example, a home-care service).

3. Managed personal budgets – At the carer's request, the LA either directly provides services to the value of the PB or places the budget with a third party/provider under a contract (for example, brokers who manage payroll and recruitment of care staff). Under this latter kind of arrangement, the contract is between the council and the third party/provider, whilst the day-to-day arrangements are between the carer and the third party/provider.

4. Commissioned support only – The LA is the sole contractor with the provider of support to the carer. The carer plays no role in the management of this relationship.

5. Information, advice, and other universal services/signposting – Carers who are found to be ineligible following assessment or decline or are not offered an assessment are provided with

information and advice, for example, referral to a third-party organisation such as a carers organisation.

6. No direct support provided to the carer – This relates to carers who were either found ineligible for support, following assessment, or refused an assessment and were not offered information, advice, and other universal services/signposting as an outcome of assessment.

7. Support involving the ‘cared-for’ person – This is where support is defined as ‘carer support’ but involves provision of support to the cared-for person. For example, respite care can meet the needs of the cared-for (to be looked after) and the carer (to have a break from their role). This category has been excluded from the total number of carers provided with support during a financial year (as shown in column ten, table four on page 150 below). These data are captured and counted as part of the support given to the cared-for, and, therefore, appears in a greyed-out column in table four. It is included because it indicates the extent to which support for the cared-for can also be thought of as support for the carer, and, therefore, highlights one of the challenges of categorising the needs of both parties as mutually exclusive.

6.2.3 ASOF data

Adult Social Care Outcomes Framework (ASCOF) collects annualised performance and survey data from all CASSRs, and measures how well care and support services achieve the outcomes that matter most to people. The ASCOF aims to give an indication of the strengths and weaknesses of social care in delivering better outcomes for people who use services.

Measures are groups by domain as follows:

1. *“Enhancing quality of life for people with care and support needs*

2. *Delaying and reducing the need for care and support*
3. *Ensuring that people have a positive experience of care and support*
4. *Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm"* (NHS Digital, 2014 - 2020).

6.2.4 Variables chosen for descriptive analysis

Domains one and three were chosen for descriptive analysis because they were specific to carers and domains two and four related to the adult with care and support needs and were therefore excluded from this descriptive analysis. Domains one and three were further sub-divided, as follows:

1C – Proportion of carers receiving self-directed support (SDS) or SDS via DP

This was a four-part measure with 1C(1B) and 1C(2B) being relevant to this analysis because they indicated the proportion of carers receiving carer-specific support. This measure was populated using SALT data returns for the number of carers receiving support as indicated in table seven, on page 156. Therefore, domain 1C is dealt with by descriptively analysing SALT data returns.

1D – Carer-reported quality of life scores (QoL)

The QoL score used in the ASOF data set comes from the Adult Social Care Outcomes Toolkit (ASCOT). The ASCOT is a suite of tools developed by the University of Kent's Personal Social Services Research Unit (PSSRU). The tools are designed to provide a reliable and valid measure of domains that are considered to make up a person's quality of life (University of Kent, PSSRU Unit, 2018). The purpose of developing the ASCOT was to devise a measure of social care outcome which could be used in the same way as the quality adjust life year (QALY) is used in health. The measure designers also sought to ensure that any measure of social care outcome that would be demonstrate rigour because it was psychometrically and cognitively tested (Netten *et al.*, 2012). Providers of social care, such as CASSRs, would then be able to use the ASCOT in a number of ways, such as experience surveys (like the SACE) and care planning to understand the impact their services were having on carers' lives, such as the ASCOF.

PSSRU defined seven domains that comprised a carer's QoL. These were: 1) Occupation; 2) control of daily life; 3) self-care; 4) personal safety; 5) social participation and involvement; 6) space and time for yourself; and 7) feeling encouraged and supported. The development of the carer QoL was psychometrically tested and validated with a randomly selected sample of carers identified through a survey of people receiving adult social care support from CASSRs in England. The sample consisted of 387 carers who took part in either a face to face or telephone interview. Data that captured characteristics hypothesised to contribute towards QoL were collected. These included socio-demographic carer and cared-for characteristics, the nature of the caring role, and measures of carer experiences, and impact of the caring role on the carer's life. Statistically significant relationships were found between these variables using regression analysis to test the construct validity of the QoL scale. A Cronbach's alpha of 0.87 indicated that the characteristics were a reliable measure of QoL (Rand *et al.*, 2015).Table four below lists each of the domains and how they were defined by PSSRU.

The survey element of the ASCOF constructed a three-part Likert QoL scale based on responses to six questions from the SACE, that aligned with six out of the seven domains defined above by the PSSRU at the University of Kent. The excluded domain from the QoL summated scale is 'space and time to be yourself'. This domain is defined as *"the carer feels that s/he has enough space and time in everyday life to be him/herself away from the caring role and the responsibilities of caregiving"* (Rand *et al.*, 2015). No explanation is offered by

ASCOF survey methodologists why this domain is excluded from the QoL scale construction.

Higher QoL scores indicate better quality of life; and carers are asked the following six questions:

1. Asks carers how much time they can spend on things they value. With one denoting *'I'm able to spend my time as I want, doing things I value or enjoy'*, two *'I do some of the things I value or enjoy with my time but not enough'*; and three '*I don't do anything I value or enjoy with my time'* (NHS Digital, 2014 - 2020)

   Value is defined as ability to access formal employment, voluntary or unpaid work, caring for others and leisure activities. This question aligns with the PSSRU 'occupation' domain (see table four below for a definition of each domain). It is also possible to see how these questions relate to the indicators of wellbeing defined by the Care Act (2014) guidance (also listed in table four below). Question one, on how much time carers have to spend on things they value relates to two of the wellbeing indicators in the Care Act guidance (a) 'participation in work, education, training or recreation' and (I) 'the individual's contribution to society (voluntary or unpaid work)'.

2. Asks how much control carers feel they have over their daily lives, with one representing *'I have as much control over my daily life as I want';* two *'I have some control over my daily life but not enough'*, and three *' I have no control over my daily life'.* This question corresponds with PSSRU domain 'control over daily life' and with wellbeing indicator(d) from the Care Act which states 'control by the individual over day-to-day life'

3. Asks *'How much time you feel you have to look after yourself'*. This question is quantified in relation to getting enough sleep, or eating well, with one representing *'I look after myself',* two *'sometimes I can't look after myself well enough', and* three *'I feel I am neglecting myself'.* This question corresponds PSSRU domain 'self-care' and with wellbeing indicator (b) 'physical and mental health and emotional wellbeing'.

4. Asks carers how safe they feel from fear of abuse, being attacked or other physical forms. Item one *'I have no worries about my personal safety',* two*, 'I have some worries about my personal safety'*, and three *'I am extremely worried about my personal safety'.* This question corresponds with PSRRU domain 'personal safety' and wellbeing indicator (c) 'protection from abuse and neglect'.

5. Asks carers to rank how much social contact they have with people they like with one indicating *'I have as much social contact as I want with people'*, two *'I have some social contact with people but not enough',* and three *'I have little social contact with people and feel socially isolated'.* This question aligns with PRSSUR domain 'social participation and involvement' and two wellbeing indicators (f) 'social and economic wellbeing' and (g) 'domestic, family and personal relationships.*'*

6. Asks carers to think about the amount of encouragement and support they receive in their caring role with one denoting *'I feel I have encouragement and support',* two, *'I feel I have some encouragement and support but not enough'* and three *'I have no encouragement and support'.* This question aligns with PSSRU domain 'feeling encouraged and supported and corresponds with wellbeing indicator (d) 'control by the individual over day-to-day life', which encompasses the extent to which carers feel they have control over support provided and the way it is provided.

Table 4 ASCOT domain descriptions [© PSSRU at the University of Kent]

Carer QoL Domains	**Description**	**Care Act (2014) wellbeing indicators (a-h)**
Occupation	The carer is sufficiently occupied in a range of meaningful and enjoyable activities whether it be formal employment, unpaid work, caring for others, or leisure activities	e) Participation in work, education, training, or recreation
Control over daily life	The carer can choose what to do and when to do it, having control over his/her daily activities	d) Control by the individual over day-to-day life (including over support provided and the way it is provided)
Personal safety	The carer feels safe and secure, where concerns about safety include fear of abuse, physical harm or accidents that may arise as a result of caring	c) Protection from abuse and neglect
Social participation and involvement	The carer is content with their social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends and family, and feeling involved or part of a community, should this be important to the carer	e) Social and economic wellbeing d) Domestic, family, and personal relationships
Space and time to be yourself	The carer feels that s/he has enough space and time in everyday life to be him/herself away from the caring role and the responsibilities of caregiving[4]	e) Participation in work, education, training, or recreation
Feeling encouraged and supported	The carer feels encouraged and supported by professionals, care workers and others, in their role as a carer	d) Control by the individual over day-to-day life (including over support provided and the way it is provided)

Source: University of Kent and PSSRU

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[4] This ASCOT domain is not used by scale developers to form the ASCOF QoL score

3B – Overall satisfaction of carers with Social Services

This measure showed the proportion of carers who were satisfied with the level of support they or the person they cared for had received from social services. This was calculated from data collected in the SACE.

The relevant question drawn from the SACE that measures overall satisfaction was Question 4: "*Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?* Drawn on an eight-point Likert scale, ranging from *'I am extremely satisfied'* to *'I am extremely dissatisfied'* (including a reference category of *'we haven't received any support or service from Social Services in the last 12 months');* the measure is defined by determining the percentage of all those responding who identify strong satisfaction, by choosing the answer *"I am extremely satisfied"* or the answer *"I am very satisfied".*

This question does not directly reference PBs as a method of support and leaves it up to the respondent to define support. No prompts are offered in how support should be interpreted. This makes it impossible to ascertain whether particular types of support are associated with satisfaction, such as a PB or other factors, such as availability of adult social care for the cared-for.

3 C – Proportion of carers included in discussions or decisions about the cared-for

This measure shows the proportion of carers who report that they have been included or consulted in discussions about the person they care for and is calculated from data collected in the SACE.

The relevant question drawn from the Carers Survey is Question 15:

"In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?"

This measure reflects the experience of carers in how they have been consulted by social care staff. Involvement in design and delivery of services and being treated as partners in care is associated with a reduction in the breakdown of care according to findings accompanying the ASCOF data sets (NHS Digital, 2014 - 2020). It is plausible to hypothesise that carers will feel more included and consulted in discussions about the support provided to the person they care for, because the Care Act (2014) imposes a new duty on LAs to offer a joint assessment of need, often referred to as a 'whole family approach' to understanding the needs of the family in the round rather than individual and separate assessments of service user and carer.

The carer-specific ASOF domains are used to describe the frequency and distribution of QoL scores, satisfaction with Social Services and feeling included in discussions or decisions about the cared-for between 2014 and 2020.

6.2.5 Survey of Adult Carers in England (SACE)

The Survey of Adult Carers in England (SACE) is a biennial cross-sectional survey conducted by CASSRs, which surveys the opinions of people with caring responsibilities over the age of 18. It covers a range of topics suggested to be representative of a balanced life alongside caring. The most up-to-date survey year (2018/19) publicly available was used in order to carry out a linear regression analysis. Data from 2020/21 survey were not publicly available at the time that the analysis was carried out. Carers are included, if during the previous 12 months, they have:

- been assessed or reviewed by social services
- received respite support
- received another form of carer support (as defined by the six-part list in section 4.4 below) (NHS Digital, 2014 - 2020).

The main areas the SACE collects data on, are:

- the carer
- experience of support and information received
- the impact of caring on quality of life
- the person receiving care (NHS Digital, 2014 - 2020).

6.2.5.1 Independent variables chosen for regression analysis

The independent variables chosen for the secondary analysis of the 2018/19 SACE data set were based on their appropriateness for testing hypothesis five, that, having a PB is associated with improved wellbeing scores. Variables with missing and 'record suppressed' (this denoted sensitive data) were removed. This applied to the age, gender, and ethnicity variables only. Although the research question asks if PBs promote wellbeing, the analysis also included age, gender, and ethnicity as control variables. This was to offer a more detailed analysis to identify other possible explanatory variables that may be associated with subjective wellbeing scores. Given the evidence of social inequalities of caring it is plausible to hypothesise that female carers, and those from ethnic minority backgrounds, will report lower levels of wellbeing compared with their male and white counterparts. SACE data do not collect any other socio-economic characteristics, such as income or social class, thus it was not possible to include any variables beyond gender, age, and ethnicity of carers in the sample receiving support.

The '*SupportToCarer*' variable in the survey indicated the six ways in which carers could receive support (as listed in section 6.2.2. of the methods section above). This variable was recoded into binary form by recoding values one to three as 1 'PB'. Items one to three represented the three ways in which a PB could be taken with 1 '*DP only'*; 2 '*Part DP''* and 3

‘*Managed PB’*. Items four to six were recoded as 0 ‘No PB’. They represented the other ways in which support could be received that did not involve the administration of a PB. They were: 4 ‘*Commissioned support only’*; 5 *‘Information, advice and other universal services’* and 6 *‘No direct support to the carer’*. Recoding the *‘SupportToCarer’* variable in binary form allowed for comparison between carers in the sample who received a PB, and its association with wellbeing, and those who did not receive a PB. This would indicate the strength and direction of the association between PBs and wellbeing.

Gender was recoded into binary form, male 0 and female 1 to give a reference category so that comparison can be made between men and women in the sample. Although the research question did not directly ask if PBs impacted men and women differently, it is useful to explore the effect of gender on wellbeing because of the gendered nature of caring, and significant literature that discusses the disproportionate effects of caring on women compared with men (Barnes, 2006; Dalley, 1996; Finch, 1983; Finch, 1989; Folbre and Nelson, 2000; Ungerson, 1997). It also allowed the study to model whether gender played a part in the extent to which PBs were associated with wellbeing.

The age variable remained unchanged with two categories, one representing carers between the ages of 18 and 64 and those aged 65>. Category labels were recoded so that 0 represented those carers aged between 18 to 64, and 1 respondents aged 65 years and over. Again, this provided a point of reference in the analysis stage which indicated if moving between categories impacted upon survey respondents’ wellbeing differently.

Ethnicity was originally coded in the survey into two categories: ‘white’ and ‘BAME’ which refers to Black, Asian, and other Minority Ethnic Carers. Although it is recognised that BAME is no longer a term used to describe people of different ethnicities, it is used in this thesis as a reference category for coding purposes. BAME was recoded as 0 and white as 1; again, to act as a reference category for analytical purposes.

6.2.5.2 Dependent variable

Questions from the 2018/19 SACE survey year that aligned with indicators of wellbeing defined in the Care Act (2014), were summated into a scaled wellbeing outcome variable. The chosen questions were also those used by ASCOF survey methodologists to construct the carer QoL scale (listed in section 6.2.4 above) and outlined again below. PB is treated as a dichotomous variable with a binary scale with 0 representing sample respondents without a PB, and 1, those sample respondents who receive a PB as an outcome of assessment in order to carry out a linear-regression analysis.

Of central interest in phase two of this thesis was to examine whether the intentions for PBs to promote carer wellbeing, were being realised in practice across England. This lent itself well to quantitative methods and regression-based models to identify if there was an association between moving from not having a PB to having a PB and testing any effect this shift may have on subjective wellbeing scores on the newly created wellbeing outcome variable. It was possible to test whether an association exists between binary-independent and continuous-outcome variables, by carrying out a means comparison (Field, 2013).

Questions that measured wellbeing were grouped together into one (three point) summated scale, taking six questions from the 2018/19 SACE survey year that tapped into the impact of caring on wellbeing. A three-point scale was chosen on the basis that this maintained consistency with the structure and number of scale items used to create the ASCOF QoL measure.

There were, however, methodological limitations of taking this approach (Morgado *et al.*, 2018), which are discussed in the limitations of phase two in section 6.7 below. The questions used in order to create the summated wellbeing scale were as follows:

1. How much time respondents had to spend on things they valued.
2. How much control respondents felt they had over their daily lives.
3. How much time respondents felt they had to look after themselves.
4. How safe respondents felt from fear of abuse, being attacked or other physical forms of violence (wellbeing indicator (c) protection from abuse and neglect).
5. How much social contact respondents with people they liked.
6. How much encouragement and support respondents received in their caring role.

Responses to each item were made on a 3-point Likert scale with lower responses indicating better wellbeing. Point one on the scale represented respondents who repported:*"I have as much wellbeing as I want";* point two *"I have some wellbeing but not enough"* and *" I have no wellbeing"*. The scale indicated good internal consistency with a Cronbach's Alpha of 0.80. An alpha of 0.70 and above is considered a reliable scale. This means that items chosen for the scale are reliable measures of the latent variable, that is, wellbeing (Field, 2013).

Figure two below, illustrates the frequency distribution of the newly created wellbeing (latent) outcome variable.

Figure 2. Histogram showing frequency distribution of wellbeing outcome variable

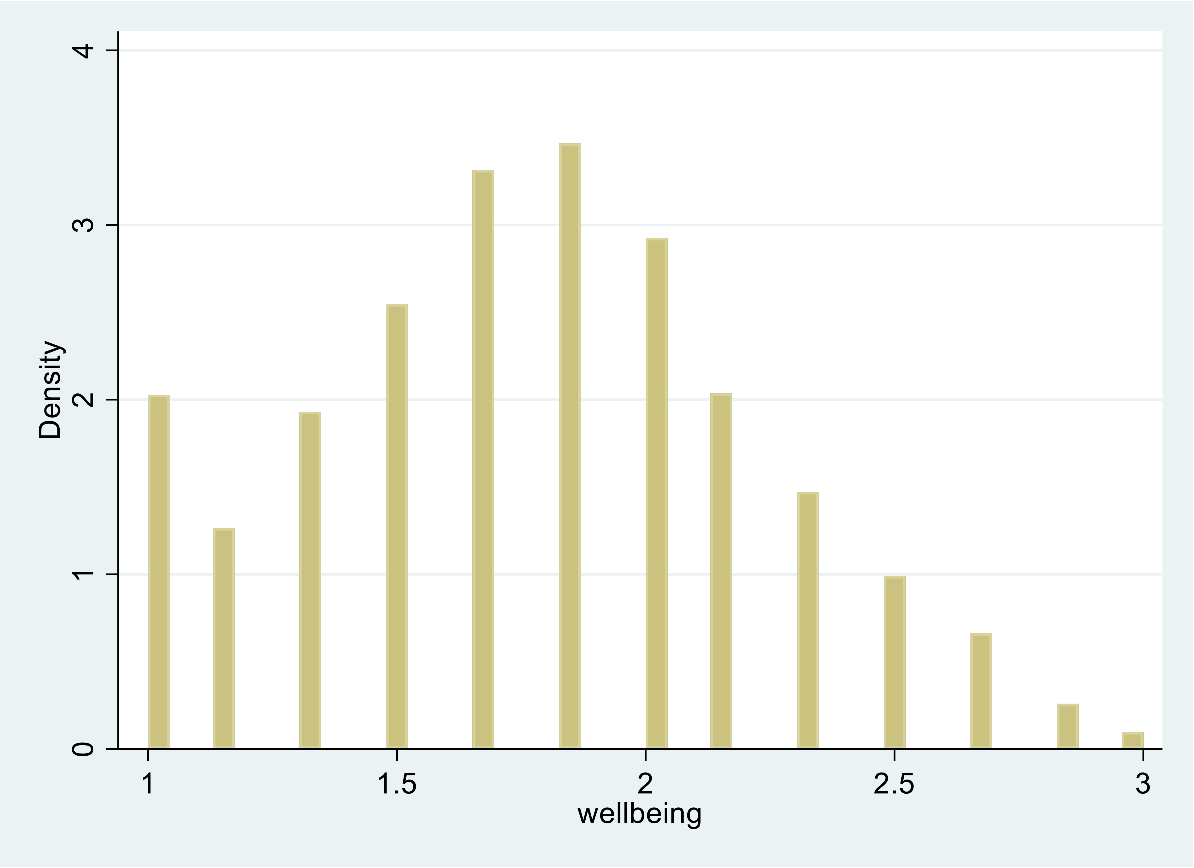


Figure two above showed a normal distribtuion curve of the outcome variable. On the X axis, wellbeing was measured on a three-point Likert scale. The Y axis indicated the numbers of carers in the sample. The scale indicated that the majority of respondents reported that they had some wellbeing, but not enough (point two), and the smallest proportion of carers reported that they had no wellbeing at all (point three). The normally-distributed outcome variable is indicative that parametric significance testing is the most appropriate method (Field, 2013).

An exploratory factor analysis was carried out which enabled the identification of scale item interrelationships. This meant that items could be grouped together where they more accurtely measured wellbeing (Field, 2013). Factor analysis identifies unobservable scale questions or variables.

A further exploration of the wellbeing (latent) variable was carried out using an oblique rotation. The assumption being, that factors would be positively correlated. For instance, you would anticipate that control over daily life would correlate with having time to spend on things you value and having as much social contact as you want being related to having encouragement and support to care.

A one-factor structure emerged, which returned an Eigenvalue of 2.39 shown by the factor loadings in table five below, and further supported by the scree plot in figure three on page 135. It is possible to deduce from table five below, that feeling safe from abuse and encouragement and support to care load more moderately compared with the other factors. This indicated that these scale items are weaker measures of wellbeing compared with the other items in the scale. Amount of social contact with others was the strongest factor-loading associated with wellbeing.

Table 5. Factor matrix illustrating a unidimensional scale

Variables	Factor 1
Time for things you value	.763
Control over day-to-day life	.791
Able to look after yourself	.721
Feeling safe from fear of abuse	.414
Amount of social contact with others	.802
Encouragement and support to care	.682

Table five above presents evidence of unidimensional scale (Field, 2013).

6.3 Reporting wellbeing central tendency and level

One of the important technical and analytical considerations for this phase of the thesis was how to report subjective wellbeing outcome levels. The decision to use a summated scale was made on the basis that question responses that comprised the ASCOF QoL measure and

SACE questions, were similarly designed around a three-point scale, thus, creating a wellbeing outcome variable using a three-point scale demonstrated systematicity and congruence. The next consideration to make was the frequency of responses because frequency informs the analytical strategy. The choice lay between representing responses to wellbeing as categories (treating wellbeing as a categorical outcome variable), that is, the number of carers who choose between categories one to three, or summarising levels of wellbeing via a measure of central tendency such as mean, median or mode (treating wellbeing as a continuous outcome variable). There are strengths and limitations to both methods as outlined by the Organisation for Economic Co-operation and Development (OECD), in its guidance on measuring subjective wellbeing, which informed my analytical decision to treat wellbeing as a continuous variable (OECD, 2013).

Of course, these technical and analytical considerations for phase two of the thesis, work on the assumption that wellbeing is a concept that can be measured in an objective sense. It presupposes that factors that comprise wellbeing are commonly accepted and understood to be fact. That wellbeing is an essential state. However, it has been shown, in the genealogical analysis of wellbeing in Chapter Five, that it can be problematic to conceptualise wellbeing in this way, because it neither takes account of the subjective knowledge of what wellbeing means to the individual, nor its dynamic state, which can shift over time as carers' life circumstances change, and they age.

Treating wellbeing as a categorical variable respects the ordinal nature of wellbeing, in that there is no mathematical meaning between wellbeing scale items. For example, there is no way to measure the difference between feeling you have as much wellbeing as you want and not having any wellbeing at all. In that, there is no assumption made that the difference between points one and two on the wellbeing scale are the same as that between two and three. The drawback with this approach, however, is that with a small three-point scale, it does not reflect the number of carers whose wellbeing falls in between these items and creates an artificially constructed boundary between items that does not reflect the breadth of carer responses.

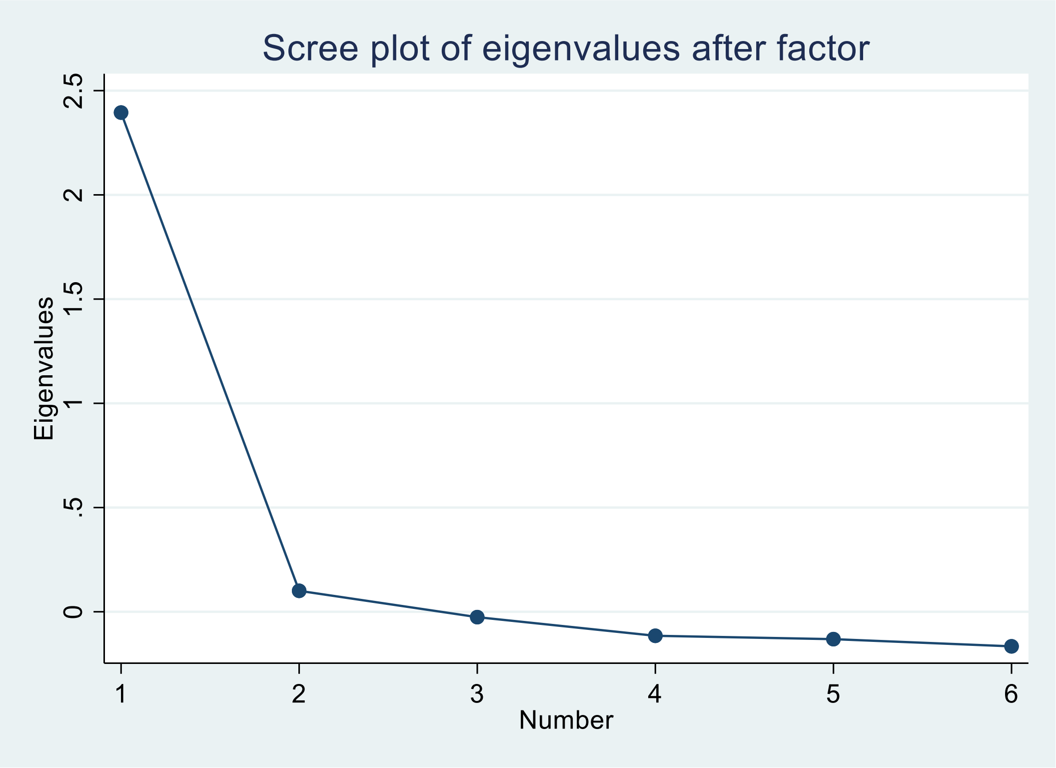
The OECD published guidance in 2013 on the strengths and limitations of measuring wellbeing using different approaches. They suggested that measures of central tendency, specifically the mean, provide a useful summary statistic of the level of wellbeing being measured. However, this required the treatment of wellbeing as continuous rather than a categorical variable when most measures of wellbeing are assumed to be categorical.

Evidenced suggested that treating wellbeing as a continuous variable, in association -based analyses (used in this thesis), did not lead to significant differences between the conclusions of research from categorical and continuous based strategies (Diener *et al.*, 2012; Frey and Stutzer, 2000). Treating wellbeing as a continuous variable also provided a more intuitive measurement of wellbeing compared with categorical-based studies. The limitations of treating wellbeing as a continuous variable were that analysis could be affected by outliers and provided no distribution of the outcome. However, this could be overcome by complementing the mean with information on the distribution of data. This allowed graphical illustrations to be used, such as the histogram (figure two on page 135) showing the distribution of the newly created wellbeing variable.

On the basis that no significant differences were found between continuous and categorical treatment of wellbeing variables, and continuous providing a more intuitive measure than using categories, a decision was made to treat wellbeing as a continuous variable. Where outcome variables are continuous, a linear regression modelling strategy is used (Field, 2013). This tested whether an association existed between moving from not having a PB to having a PB, and the effect of this change on carer-wellbeing scores.

I tested the conclusions from the OECD evidence, that, no significant differences existed between the treatment of wellbeing as either a continuous or categorical outcome variable and found this to be true. I carried out both an ordinal and linear regression analysis, treating my outcome variable as both categorical and continuous, and found the same results.

Figure 3. A scree plot showing a one-dimensional scale to measure wellbeing



The scree plot above graphs the Eigenvalues against the factor numbers. It is possible to see that factor one explained most of the total variance amongst the observable scale items, compared with factors two onwards. This demonstrated that a one-factor structure emerged. You can see how the elbow flattened significantly from factor two onwards: meaning that successive factors accounted for smaller amounts of total variance between items being measured. Factor two returned an Eigenvalue of 0.90. Eigen values below one are indicative of no other factors measuring characteristics observed in scale items, and was, therefore, discarded from the analysis (Field, 2013).

6.4 SACE analysis and statistical tests

This section sets out the statistical tests used to test the significance of findings and the assumptions underpinning the modelling strategy used in the inferential analysis of SACE data.

One of the functions of inferential statistics is, that you are looking to see if the effect of the predictor (or independent) variables (PB) on the outcome variable (wellbeing) is statistically significant in the population from which the sample is drawn. Can I generalise the findings from this secondary analysis of survey data for carers in the population?

Generalising findings at population level is carried out by hypothesis testing. To be able to determine whether or not hypothesis five hold true, that having a PB improves wellbeing, a statistical test of significance is required. The hypothesis test determine whether or not the coefficient for PB is different from zero. This is referred to as the null hypothesis. If the coefficient is zero, then there is no statistically-significant association between PBs and wellbeing (Field, 2013).

The type of test chosen depends upon the comparison being made, the types of variables being used (continuous or categorical) to inform the comparison, and the distribution of the outcome variable. Statistical tests are either parametric or non-parametric. Where outcome variables are normally distributed, a parametric test is chosen, and figure two in section 6.2.5.2 confirms that wellbeing is a normally distributed outcome variable. Therefore, a regression analysis is the correct statistical test to use because wellbeing is both normally distributed and is treated continuously for the purposes of comparison (Field, 2013).

The term significant refers to the statistical significance at the 95% level. Significance testing was carried out to test whether an association existed between the independent and outcome variables. The model tested the association between PBs and wellbeing after controlling for other socio-demographic characteristics: these were gender, age, and ethnicity.

Linear regression attempted to model the association between PB as an independent variable, and wellbeing as an outcome variable, by fitting a linear equation to the observed data. (Field, 2013).

A linear regression line has an equation of the form $y= a+bX$ where x is the explanatory/independent variable (PB), and y is the dependent or outcome variable (wellbeing). The slope of the line is b, and a is the intercept (the value of $\mathbf{y}$ when $x = 0$). Regression analysis allows the researcher to estimate the values of the dependent variable from the observed values of the independent variable (Field, 2013).

The assumption underpinning this model is the null hypothesis. A null hypothesis is a type of hypothesis used in statistics that proposes that there is no difference between certain characteristics of a population. The researcher attempts to disprove this assumption by testing whether the observed variation on the outcome between PBs and wellbeing could have happened by chance, or, whether it is likely to reflect some ‘real’ differences in the eligible population.

A p-value is the probability of the observed result occurring due to chance alone. A p-value of less than 5% is conventionally taken to indicate a statistically significant result ($p<0.05$).

The statistical tests do not infer cause and effect. Tests are not designed to say that PBs cause your wellbeing to go up or down, but, rather, to determine whether there is an association between the two that is considered not to be the random happenings of chance, but, rather, indicative of an association existing between PBs and wellbeing in the caring population.

Interpretation of the correlation coefficient (r) provides information about the strength and direction of the relationship between PBs and wellbeing. R =1 would demonstrate a perfect linear relationship. The closer r is to 1 or -1 the stronger the relationship. R=0 would indicate no linear relationship, and r<1 would illustrate a negative relationship (for every one unit increase in the predictor variable there is a corresponding one unit decrease in the dependent variable). Where r>0, a positive relationship is indicated (for every one unit increase in the predictor variable there is a corresponding one unit increase in the dependent variable). In the context of this thesis, a positive relationship would indicate that moving from having no PB to having a PB (two value variable) would increase your wellbeing score, and vice versa. However, because the independent variables (PB, gender, age, and ethnicity) are categorical and binary, the regression coefficients are interpreted in reference to the numerical encoding of these variables. In the context of this phase of the thesis, having no PB, being male and BAME, are all coded as 0, and, therefore, act as reference category (or dummy variables), and defined first in relation to the relationship between predictors and outcome.

The initial judgement of a possible association between two variables should always be made on the basis of a scatter plot. This type of plot will show whether the relationship is linear or non-linear (Field, 2013).

6.5 SACE population and sample

The eligible population of the 2018/19 SACE includes all carers aged 18 or over who are known to CASSRs and who are also caring for somebody over the age of 18. The total eligible population for the 2018-19 SACE survey was N = 292,360, from which a sample of n = 136,095 people was drawn. Samples are drawn by individual CASSRs, and a total of 50,800 responses were received for all CASSRs in England during 2018/19. This represented a 37% response rate. CASSRs draw random samples from their own databases where carers are known to them.

The sample of carers receiving a survey is smaller than the eligible population because not all carers sampled are eligible to complete a survey. Carers who are subject to safeguarding concerns: former carers where the cared-for may have died in that year, or those who may be in dispute with their LA, are not surveyed.

In 2016-17, the eligible population increased to 341, 515 and n= 136, 920. This was to accommodate carers who had not been assessed or reviewed during the previous 12 months, reflecting the duty placed on LAs to make information and advice available to carers (this is identified by the *'no direct support to carers'* category in table six, column nine on page 150, and comprises two values). Value one reflects respondents who did not meet the eligibility criteria for assessment and PB, and value two: respondents who declined assessment. The survey seeks carers' opinions on several topics that are indicative of a balanced life alongside their caring role.

The sampling frame, therefore, contained all carers aged 18 and over who either received *"support direct to carer" or "no direct support to carer",* irrespective of whether their cared-for person was eligible for support.

The SACE is a postal (self-completion) survey sent out to a random sample of carers by each of the Local Authorities in England with CASSRs. Surveys are carried out over the telephone, but face-to-face interviews can be conducted if requested by the carer. In 2018/19, two councils also piloted the use of an online survey. This was a change from the 2016/17 where all questionnaires were carried out over the telephone.

The survey is considered an important resource which demonstrates outcomes achieved for carers who are supported by CASSRs. It is used by CASSRs as a way of assessing their performance. They also use the data to inform policy decisions about carers in their area, and benchmark their performance against other CASSR comparator LAs (Association of Directors of Adult Social Services, 2020). SACE investigates whether services received by carers have supported them in their role and to have a life away from caring, such as their ability to combine work with caring or looking after other dependents such as children and seeks their perception of services provided to the person in receipt of care.

Survey question responses are weighted with eligible population estimates. Weighting is a component in survey sampling in order to ensure that a representative sample is available for analytical purposes. For example, the sample population comprising male respondents in the 2018/19 survey comprised 32%, and 68% female, whereas men make up 48% of the England caring population. Weighting, therefore, allows you to generalise your findings from the sample to the whole carer population (Groves, 2009). Similarly, 88% of sample respondents identified as white and 12% from a Black, Asian, or other minority ethnic background. This is more than the England average, where 10% of carers in England are from a BAME background, according to 2011 Census data (Office for National Statistics, 2016). The survey did not break down BAME by ethnicity, which is problematic, because it homogenises a population group which is likely to have very different experiences of caregiving. This, and other limitations of this phase of the thesis, are discussed in section 6.7 below.

The survey uses data from a sample of carers to make inferences (or estimates) about the whole population. These estimates are subject to a degree of uncertainty that can be expressed as a margin of error. The margin of error of an estimate is related to the proportion of the population that responds to the survey, as this proportion increases, the margin of error decreases. Therefore, the margin of error can be reduced by increasing the survey sample size and/or response rate. Councils are required to select a sample such that the survey results have a margin of error of less than five percentage points, and on that basis, are encouraged by NHS digital to over sample.

The selected sample is checked for carers who should not be sent a survey, for example, if the person has stopped being a carer, the carer or the cared-for person has died, or if the carer has been hospitalised, or is involved in an open-safeguarding alert or investigation. In addition, a survey is not sent if the carer is in active dispute with the council, and it is felt that sending them a questionnaire could be perceived as being unduly provocative or insensitive. Carers removed from the sample for any of these reasons are replaced with other randomly selected eligible carers.

6.5.1 SACE sample characteristics

The survey comprised a small number of socio-demographic characteristics (gender, age, and ethnicity). Women comprised the largest proportion of sample respondents in the 2018/19 SACE survey, with 68% female and 32% male. The largest age band was 55-64 years, which accounted for 23.8% of the eligible population, and the smallest group 18-24 years, accounted for only 1.6% of the eligible population. Age expressed in binary form indicated that the sample is made up of slightly more older carers, with 52% aged 65>, and 48% 18 to 64 than younger carers. Most survey respondents, 88% reported their ethnicity as white and 12% BAME. The limited number of socio-demographic characteristics and response options in binary form reduced the explanatory potential of the model. This is discussed in more detail in the limitations section (6.7) below.

6.6 Findings

6.6.1 Hypothesis 1 – SALT returns will show an increase in the number of carers receiving assessment and support in the form of a PB between 2014 and 2020

SALT performance data are descriptive data and show the total number of carers in England who have received an assessment and/or support by the type of support provided. Table six, on page 145 below, gives a breakdown of the number of carers assessed and supported from the introduction of the Act in 2014. The data show a steady decline in the number of carers being assessed by CASSRs during the time period under investigation (2014 to 2020). Of the 5.4 million carers in England, 8% received an assessment of their needs in 2014/15, but this dropped to 7% in 2019/20. This finding represents a very small number of the caring population in England being identified by CASSRs for assessment and support. Given the Act was intended to increase the recognition and support given to carers, with assessment the first step in securing that support, this initial finding suggests the reverse is happening.

Of those carers who were assessed (436, 830 in 2014/15), the data showed a 4% increase in the numbers receiving PBs in the form of DPs: rising from 17% in 2014 to 20% in 2019/20 (indicated by column four *'Direct payment only'*). However, carers were much more likely to receive advice, information, and signposting as an outcome of their assessment than a PB in the form of DP or any other form of support. Nearly half of carers assessed in 2014 (45%) received advice and information and other universal services/signposting, and this figure rose to 55.1% in 2019/20. For all other forms of support indicated in table five (*part direct payment, managed PB or commissioned support only*) the numbers are low, and reduce further over time, in the case of part DP and commissioned support, or stay the same in respect of managed PBs.

Some carers who were assessed by CASSRs received no direct support at all. This represented 24% of carers' assessment outcomes in 2014/15, which dropped to 14% of cases in 2018/19, and then rose again in 2019/20 to 15.9%. SALT data (in the 2015/16 year only) gave further granularity to those carers who were offered *no direct support following assessment*, with the inclusion of additional columns. In the 19% of cases in 2015/16 where no direct support was offered following assessment, 8% had '*no support needs'*, in other words, they did not meet the eligibility criteria for carer support. 5% '*refused assessment'*, and, in 6%, assessments were carried out but no information was offered on the outcome. This likely means, that the assessor has not entered a value on the administration system to indicate the outcome of the assessment process. This may also indicate that the carer did not receive an outcome of either eligibility or ineligibility following assessment. More than half of assessed carers in England receiving advice and information raises important questions about the efficacy, purpose, and value of the assessment and support-planning processes.

The final column, in table five on page 145, identified the number of carers who were supported indirectly by the care that was provided to the person they looked after, such as respite care. This form of carer support was captured in SALT service-user data, therefore, was greyed out, because it was not counted as a carer-specific service (explains why rows did not sum to 100).

SALT data also broke down carer support by the method of assessment and figure six on page 149 below shows the split between carers who receive a separate assessment of their need alongside those who have their needs assessed alongside the those of the cared for (joint assessment). These are useful data to present because it is possible to show whether one type of assessment is more likely to lead to a PB in the form of DP compared to another. These data were collected by CASSRs between 2014 and 2016 only.

The data showed that carers who were jointly assessed with the person they looked after were less likely to receive direct support, such as a DP, compared with those carers who were assessed separately. Three percent of carers who were jointly assessed with the cared for person in 2014/15 and 2015/16 received a PB, in the form of DP, compared with 10% of carers who had a separate carer's assessment, even though more carers were assessed jointly (41% compared with 37% in 2014/15) than individually assessed. No data on carer support by assessment method were available for 2015/16, or beyond, because these data were no longer captured by CASSRs. This finding raises important questions about the efficacy of whole-family approaches to assessment (introduced by the Care Act, 2014), which LAs are duty bound to offer, based on the evidence, that suggests that joint assessments of service users and carers leads to better outcomes for both.

Table 6. Carer support between 2014 to 2020 broken down by support provided

Year	Total number of carers assessed & supported by CASSRs each year	Total number of carers assessed & supported as a % of England total (5.4 million)	Direct payment only	Part direct payment	Managed personal budget	Commissioned support only	Information, Advice, and other universal services/signposting	No direct support provided to carer	Support involving the cared-for e.g., respite care (this column is counted as part of the cared for support)
2014/2015	436,830	8%	17%	4%	3%	7%	45%	24%	13%
2015/2016	386,600	7%	17%	4%	3%	7%	50%	19%	15%
2016/2017	368,990	7%	20%	3%	3%	5%	51%	18%	14%
2017/2018	360,310	7%	20%	2%	3%	5%	55%	14%	12%
2018/2019	345,850	6%	21%	2%	3%	5%	54%	14%	12%
2019/2020	376,130	7%[5]	20%	1.6%	2.8%	3.9%	55.1%	15.9%	Missing data

Source: Community Care Statistics, Social Services Activity, England – 2014-2016 and SALT Collections, 2012019, NHS Digital

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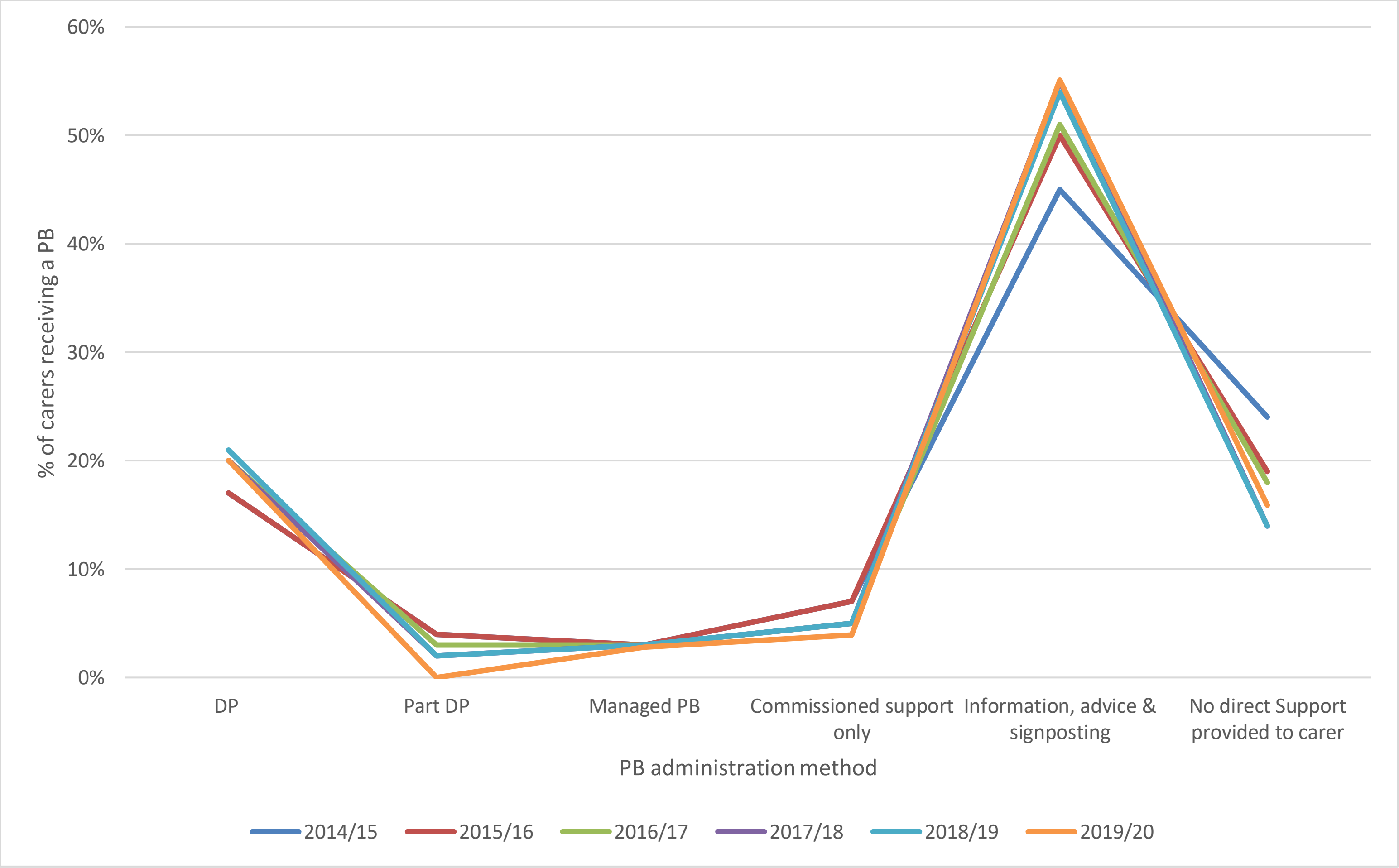
[5] Census data are ten years old, therefore, the percentage of carers assessed in 2019/20, as a proportion of all carers in England, may be significantly less than 7% reported, because it is likely that the population of people who identify with a caring responsibility may have increased over a ten-year period.

Figure four on the next page compares the different ways that carers received a PB between 2014 to 2020. It demonstrates how advice, information, and signposting was the most likely outcome following a carers assessment of all the administration methods of a PB. Over time, the number of carers receiving advice and information increased, with more than 50% of carers assessed by CASSRs leading to this outcome.

Figure five on page 148 illustrates the contrast in administration modes of PBs in 2014, compared with 2020. It shows a small increase in the number of eligible carers in 2019/20 receiving a PB, in the form of DP, compared with 2014, but only by 3%, which, in a six-year period, where PBs are considered a key way in which carers can be supported to have a life of their own alongside caring, would appear a modest increase.

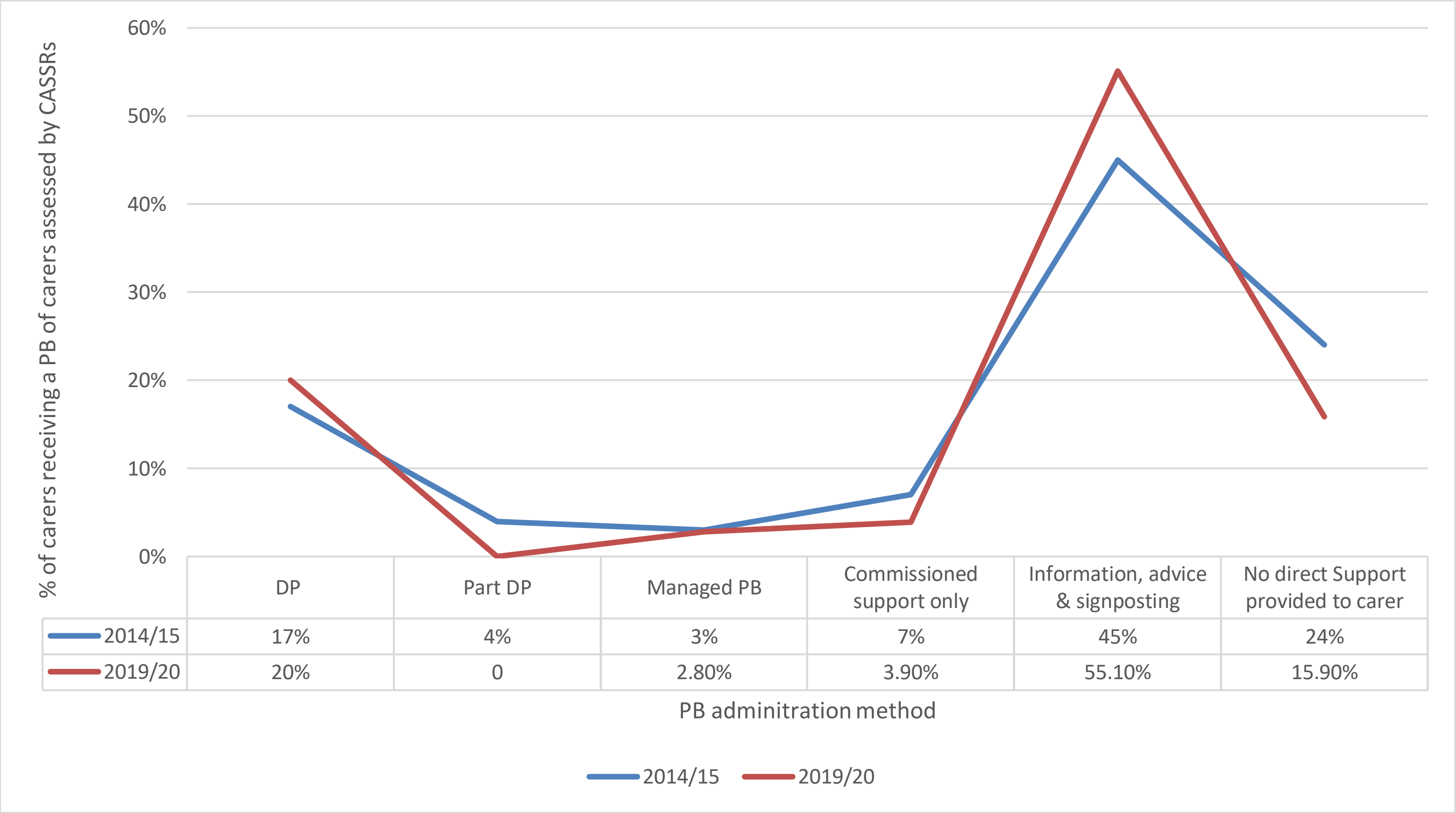
Figure 4. Percentage of carers receiving a PB by method of administration in England - 2014 to 2020



Percentage of carers receiving a PB by method of administration in England - 2014 to 2020

Source: Community Care Statistics, Social Services Activity, England – 2014-2016, and SALT Collections, 2016 – 2020, NHS Digital

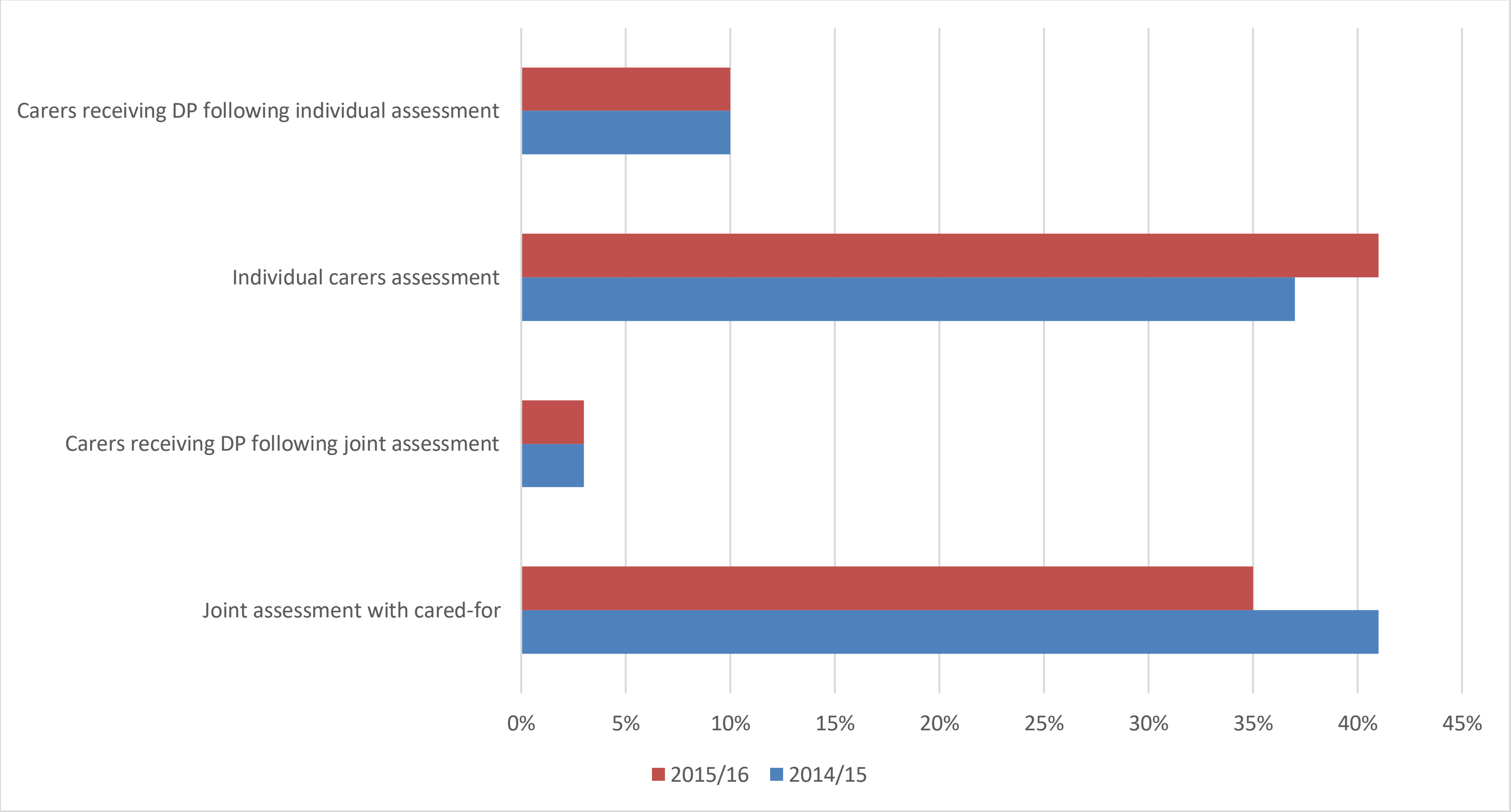
Figure 5. Percentage of carers receiving a PB by method of support 2014/15 compared with 2019/20



	DP	Part DP	Managed PB	Commissioned support only	Information, advice & signposting	No direct Support provided to carer
2014/15	17%	4%	3%	7%	45%	24%
2019/20	20%	0	2.80%	3.90%	55.10%	15.90%

Source: Community Care Statistics, Social Services Activity, England – 2014-2016, and SALT Collections, 2016 – 2019, NHS Digital

Figure 6. Carer Direct Payment by method of assessment - 2014 to 2016



Source: Community Care Statistics, Social Services Activity, England – 2014-2016, and SALT Collections, 2016 – 2016, NHS Digital

Findings from SALT data showed a steady decline in the number of carers being assessed and supported by CASSRs during the time period under investigation (2014-2020).

Hypothesis one is, therefore, rejected, based on this analysis. SALT data returns do not show an increase in the number of carers receiving assessment and support in the form a PB between 2014 and 2020. The total number of carers assessed and supported between 2014 and 2020 dropped from 8% in 2014 to 7% in 2020. What is also worthy of note was the very small percentage of carers being assessed and supported as a percentage of the total number of carers in England. Given, there are approximately 5.4 million carers in England, according to Census data (2011) for each year recorded, less than 10% of carers in England were assessed by CASSRs annually, between 2014 to 2020 (Office for National Statistics, 2016).

6.6.2 Hypothesis 2 – Carers will report increases in their QoL scores between 2012 and 2018

The QoL score is a composite measure made up of six questions from the Survey of Adult Carers in England (SACE). Table six below shows satisfaction rates from 2012/13 to 2018/19. The rationale for including data from 2012 was to reflect the start point of the SACE survey. This offered a greater length of time from which to show a trend in terms of outcome measures and their impact. It illustrates how carer quality of life (QoL) measures have steadily declined between 2012 and 2019, as lower scores represent a poorer quality of life (QoL).

Because the SACE is a biennial survey, no data were available for 2019/20. The next survey year will be 2020/21. Findings from this survey year were not publicly available at the time this analysis was updated in 2020.

Table 7. Summary of ASCOF carer-related outcome measure values: by measure and year, England 2012/13 to 2018/19

Date range	Number of carers (Eligible population)	SACE Sample size	Survey response rate	1C: Total number of carers assessed & supported as a % of England total	1D: Carer-reported quality of life score out of a maximum score of 24 (lower scores indicated better wellbeing)	3B: Overall satisfaction of carers with Social Services as a % of carers surveyed	3C: The proportion of carers who report they have been included or consulted in discussion about the person they care for as a % of carers surveyed	3D: The proportion of carers who find it easy to find information about support as a % of carers surveyed
2012/13	*	126, 950	46%	8%	8.1	43%	73%	69%
2013/14				7%	No SACE survey(NSS)	NSS	NSS	NSS
2014/15	*	131,105	44%	8%	7.9	41%	72%	66%
2015/16				7%	NSS	NSS	NSS	NSS
2016/17	341,515[6]	136,920	40.7%	7%	7.7	39%	70%	64%
2017/18				7%	NSS	NSS	NSS	NSS
2018/19	292,360	136,095	37%	6%	7.5	39%	70%	62%
2019/20				7%	NSS	NSS	NSS	NSS

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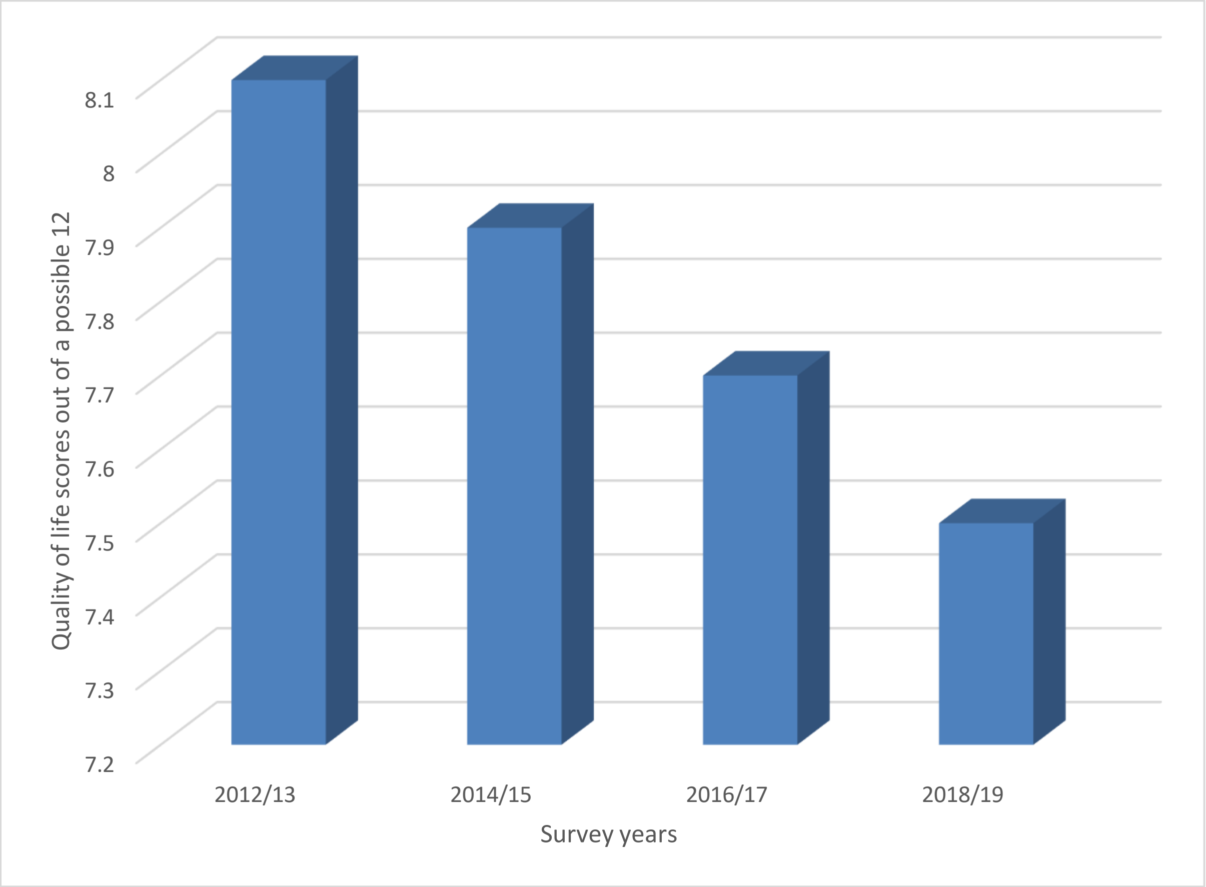
[6] Eligible population changed to include carers who had not received an assessment or review in the previous year. This was to acknowledge the Care Act (2014) duty on councils to make advice and information available to carers.

*Eligible populations were not stated in the ASCOF survey documentation.

Figure 7. ASCOF Carer reported quality of life scores - 2012 to 2019



Source: SALT, HES, NHS Digital 2012 to 2018/19

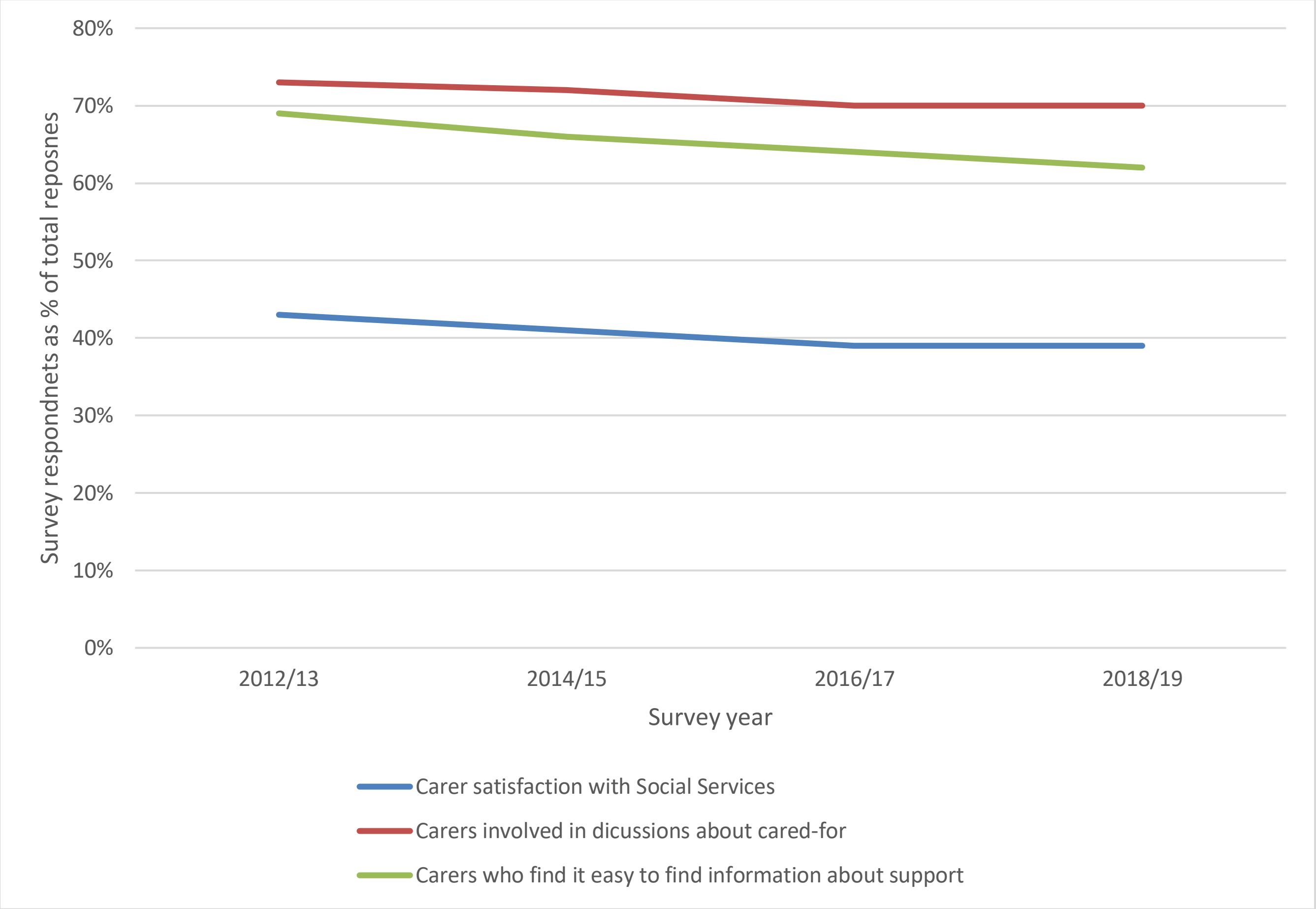
Figure eight above shows how carer-reported, quality-of-life scores have steadily declined with each survey year since the SACE survey began in 2012/13. Thus, rather than the Care Act (2014) and PBs contributing to improvements in the quality of life that carers report, there has been a reduction in every year that the survey of adult carers data were collected.

Hypothesis two, that carers will report increases in their QoL between 2012 and 2019, has been rejected by the descriptive analysis presented in these findings. QoL scores reduced from 8.1 in 2012/13 to 7.5% in 2018/19.

6.6.3 Hypothesis 3 – Carers will report increases in their satisfaction with Social Services between 2012 and 2019

A steady decline was observed in the remaining ASCOF measures relating to carers between 2012/13 to 2018/19. Satisfaction of carers with social services reduced from 43% in 2012/13 to 39% in 2018/19. Figure seven below shows care- reported outcome measures in relation to satisfaction with Social Services, depicted by the blue line. Hypothesis three, that carers will report increases in their satisfaction with Social Services between 2012 and 2019 has been rejected by this descriptive analysis. Satisfaction was defined by the percentage of carers who chose either *" I am very satisfied"* or *"I am extremely satisfied"* with the support or service that I and the person for whom I care for has received from Social Services in the last 12 months.

Figure 8. ASCOF Carer-reported outcomes - 2012 to 2019



Source: SALT, HES, NHS Digital 2012 to 2019

6.6.4 Hypothesis 4 – Carers will report improvements in their involvement and consultation in discussions and decisions about the cared-for

The proportion of carers reporting that they felt involved and consulted in discussions and decisions about the cared-for dropped by 3% between 2012/13 and 2018/19 (denoted by the red line in figure eight above).

The duty to offer joint assessments of need, in order to understand the needs of the family in the round, is not leading to carers feeling that they are more involved in the care and support arrangements of the person they look after, based upon these descriptive findings. Given, that SALT data recorded a 6% drop in the number of joint assessments from 41% in 2014/15 to 35% in 2015/16, this may offer some indication why carers feel less involved, if the cared-for assessment is happening independently of the carer’s assessment. Even where carers do have their needs assessed together with the service user, the SALT data shows that carers are less likely to receive a PB from this mode of assessment compared with a separate carer’s assessment. Hypothesis four, that carers will report improvements in their involvement and consultation in discussions and decisions about the cared-for is rejected by this descriptive analysis.

6.6.5 Hypothesis 5 – Having a PB increases subjective wellbeing scores

Hypothesis five was the only hypothesis to be tested for statistical significance, using data from the 2018/19 SACE survey. In this survey year, 38% of carers received a PB as either a DP, part DP, or managed PB, and 62% received no PB, and therefore, received advice and information, or no support at all as an outcome of their assessment. The total eligible population for the survey was 292,360 carers known to CASSRs across England, of which a sample of 136,095 was drawn, and 50,800 carers responded. This represented a response rate of 37%.

By carrying out a two-way cross tabulation using, Stata 16.1, this illustrated that more carers without a PB reported better wellbeing scores than those with a PB. On the newly created wellbeing scale, 66% of survey respondents reported “*I have as much wellbeing as I need*” (point three on the scale), the highest value on the wellbeing scale. This compared with 59% of respondents who received a PB and reported the same scale point.

Table 8. Two-way table with measures of association between PBs and wellbeing

Wellbeing score (scored 1-3)	No Personal Budget	Personal Budget
I have as much wellbeing as I need	66%	59%
I have some wellbeing but not enough	34%	41%
I have no wellbeing	0.4%	0.5%

Table eight above shows an association between the newly created, three-part Likert wellbeing scale, and sample respondents with and without a PB. Respondents who report that they have some wellbeing, but not enough, is higher for those carers who have a PB compared with those who do not. More carers in receipt of PBs say they do not have enough wellbeing compared with those carers in the sample without a PB.

6.2.3.2 Linear regression modelling

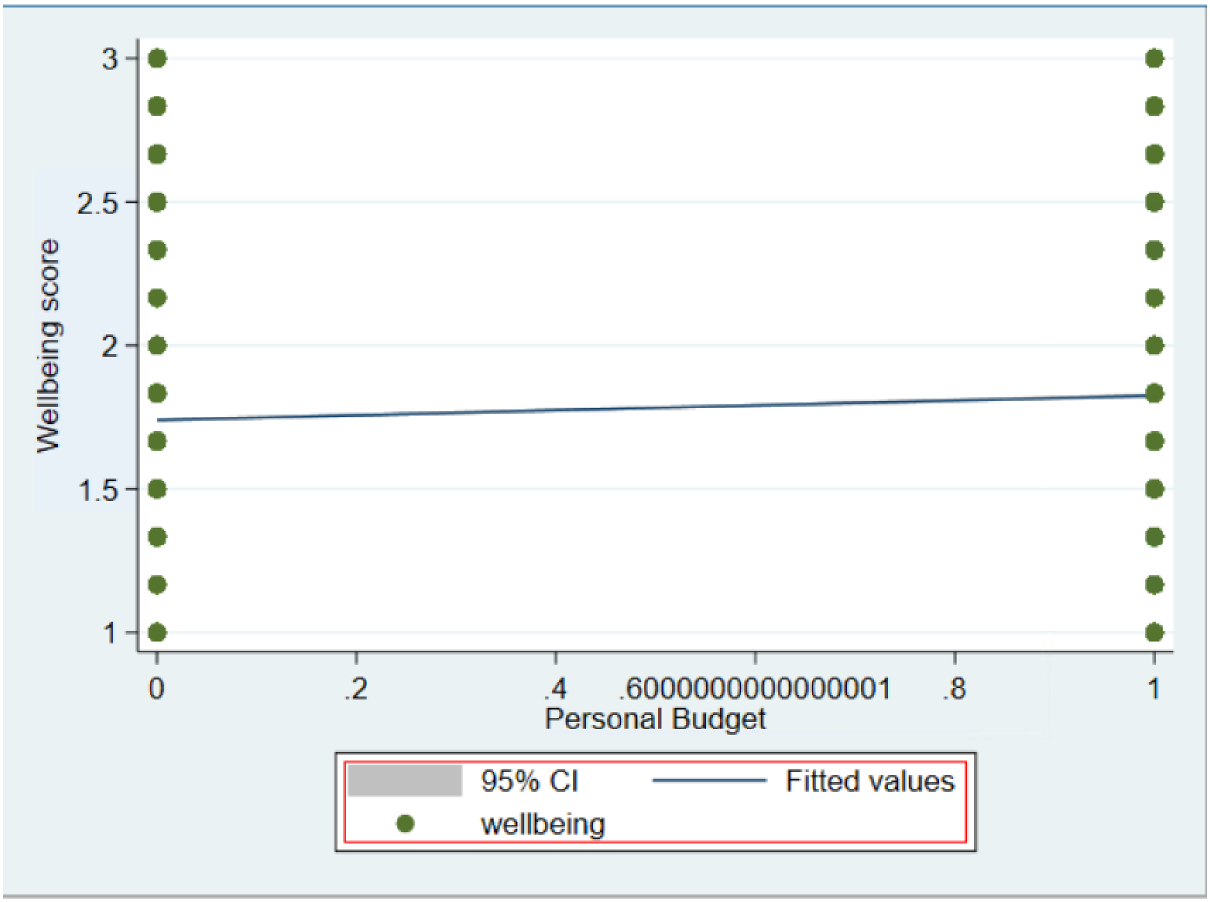
To be able to determine whether or not hypothesis five, that having a PB improves wellbeing holds true or not, a statistical test of significance was required. As discussed, regression analysis was considered the correct test based upon the comparison being made, the types of variables being used to inform the comparison, and the distribution of the outcome variable (Field, 2013).

Linear regression analysis could determine whether an association existed between carers receiving a PB and reporting improved wellbeing scores using data from the biennial 2018/19 SACE sample. Specifically, this was to test whether PBs were positively correlated with wellbeing. While PB was the main variable for interest, the model controlled for other socio-demographic characteristics, which were available in the survey data (in binary form only), these were: gender; age and ethnicity, to identify whether these factors held any explanatory power in determining wellbeing scores.

Figure nine below showed that there was a positive correlation between having a PB and wellbeing. The fitted line indicated a very small upward trajectory. On the X axis, moving from 0 (representing sample respondents without a PB) to one, indicated that those who were in receipt of a PB reported slightly higher wellbeing scores compared with carers in the sample without a PB. The Y axis illustrated the three-point wellbeing scale, with higher scores representing poorer wellbeing. Therefore, suggesting that having a PB does not improve a carer's wellbeing score.

The fitted line showed the mean wellbeing score, and the data points either side of the line indicated the dispersion of those scores around the mean. The fitted line indicated the strength of association between the independent and dependent variables. The line trajectory suggested a very weak association between PBs and their effect on wellbeing scores. This was indicative of PBs not being a strong indicator of wellbeing. This is suggestive of other socio-demographic factors having a stronger association with wellbeing scores, such as income, occupational status, and physical health.

Figure 9. Scatterplot – Regression of Personal Budgets alongside wellbeing 2018/19



Multiple-regression analysis was used to test the hypothesis that wellbeing could be predicted by PBs, whilst controlling for gender, age, and ethnicity. The results, shown in table nine below, demonstrated a positive, significant effect for PBs on wellbeing.

The regression coefficient (or slope line) represented the mean change in wellbeing when you moved from having no PB to having a PB. The wellbeing score increased by 0.078 points on the wellbeing scale. Because higher scores represented poorer wellbeing, it could be said that having a PB was not associated with improved wellbeing. This was a statistically significant finding (p=0.000).

The R-squared (0.0218) showed that two percent of the variance in wellbeing could be explained by PBs, gender, age, and ethnicity. This was a very low effect size, indicative of other factors having greater explanatory power in determining what contributes towards a carer’s wellbeing. As regression analyses are comparisons of group means, we can use Cohen-classified effects sizes as a guide for the magnitude of effect (referred to as Cohen’s ‘d’) categories effect sizes as: 1) small (d=0.2), 2) medium (d=0.5), and, 3) large (d≥0.8) (Sullivan and Feinn, 2012)

Introducing the socio-demographic control variables into the model did not indicate a better fit; although the introduction of gender did reinforce the empirical evidence that women are disproportionately impacted by caring compared with men ((Bailey, 1975; Barnes, 2006; Dalley, 1996; Finch, 1983; Ungerson, 1997), as female carers reported poorer wellbeing scores compared with male carers in the sample. The regression model indicated that being female increases your wellbeing score by 0.43 units on the scale.

As sample respondents aged, their wellbeing scores improved, indicating that older carers reported better wellbeing scores compared with younger carers in the survey. Moving from the 18 – 64, to the 65≥ age categories reduced wellbeing scores by 0.08 units. Lower scores represented better wellbeing. Age, as a predictor variable of a carer’s wellbeing score, did not suggest an improved fit compared with gender or PBs.

Finally, introducing ethnicity into the model demonstrated that white carers reported better wellbeing scores compared with carers in the survey who identified as Black, Asian, and Minority Ethnic (BAME). The SACE survey did not break down ‘BAME’ category any further, therefore, was a crude variable with which to predict wellbeing scores. However, it demonstrated that being white was associated with lower wellbeing scores by 0.04 units.

The adjusted R squared is an estimate of the effect size, which at 0.0217 (two percent) would be considered very low. Effect size looks at measures of association between two variables, therefore, the model showed that PBs have a very small effect upon a carer's wellbeing score. Effect size is an important product of any modelling strategy. Effect sizes describe the magnitude of the relationship between variables. In the context of this thesis, both the effect of PBs on a carer's wellbeing (R squared), and how much the PB affects a carer's wellbeing, are both very low. Although we can reject Hypothesis five, that PBs improve carer wellbeing, it is a very weak predictor of wellbeing scores, and therefore limits the inference that can be drawn for this finding.

The very low variance in the model may, in part, be explained by the way in which survey characteristics were categorised in the survey. For example, age and ethnicity variables were coded as two categories (18-65 or 65>, and BAME or white). This has the effect of 'flattening' the data which reduces the explanatory power of a statistical model. Having greater variation within variables, such as a broader range of age and ethnicity categories, may have shown greater variation between the independent and dependent variable.

Table 9. Regression Results for Wellbeing scores (standard deviations from the mean)

Variable	**Coefficient**
SupportToCarer (PB)	0.078*** (0.003)
Gender (female)	0.043*** (0.005)
Age group (65>)	-0.082*** (0.005)
Ethnicity (white)	-0.043*** (0.005)

Standard errors are reported in parenthesis
*,**.*** indicates significance at the 90%, 95% and 99% level, respectively.

R-squared = 0.0218
Adjusted R-Squared = 0.0217

6.7 Limitations of the quantitative study

There were a number of methodological limitations with this secondary analysis of carer-specific, performance-and-survey data, which affected the strength of these findings that PBs do not improve carer wellbeing scores.

Using descriptive findings for hypothesis testing is limited, because hypothesis testing is a form of inferential statistics that allows the researcher to generalise findings from a representative sample at population level (Field, 2013). In contrast, descriptive statistics summarise the characteristics of a data set, and therefore cannot be generalised to a broader population. However, using descriptive statistics, for example, to measure the number of carers who received assessment and support since the introduction of the Care Act (2014) was sufficient to be able to address whether hypothesis one held

Another limitation is the use of cross-sectional survey data as a measurement tool. It is well documented that using cross-sectional data as a measure of effect (PBs on wellbeing) is limited, because of the exclusion of time as a change variable (Longhi and Nandi, 2015). The SACE survey is cross-sectional, and therefore captures a snapshot effect of the impact of caring on quality of life and experience of support. It cannot reflect, for example, on how carer wellbeing may be shaped by the ageing process, nor account for conceptions of wellbeing as a dynamic state, which may shift over time, which panel data can do.

Finally, there are limitations in the analytical decisions I took in creating a wellbeing outcome variable which limited the explanatory power of the linear regression model used to test hypothesis five. Creating a three-point outcome scale forces responses to questions into a small number of categories which may increase the error rate. You would not anticipate in the caring population that wellbeing could be reduced to three categories. Although the scale did indicate a moderately strong internal consistency, with a Cronbach's Alpha coefficient of 0.80.

6.8 Summary

This chapter has shown, using linear regression modelling, that the Care Act's (2014) intention to promote the wellbeing of carers using PBs as a lever, is not being realised in practice. ASCOF survey data indicated that carer QoL declined during the time period under investigation, providing further evidence.

Carer's assessment rates have declined year on year since the Act was introduced in 2014. The small numbers of carers receiving an assessment of their own needs represented just 7% of the total caring population in England in 2019/20. Performance data illustrated how the mode of assessment is associated with the outcome, because carers are more likely to receive a PB as an outcome of assessment when their needs are assessed separately from the service-user assessment. This contradicts the guidance accompanying the Care Act (2014), which states that joint assessments are an effective way to take account of the needs of the whole family (*The Care Act*, 2014).

The Care Act (2014) claim that PBs can promote wellbeing is not supported by this regression analysis. Carers surveyed who received a PB reported poorer wellbeing scores compared with those not in receipt of a PB. This was a statistically significant finding, at the 95% confidence interval.

Given that just 6.4% of the total caring population in England are known to all CASSRs across England (between 2014 and 2020), suggests any number of possibilities. It may indicate that carers continue not to identify with the label, and therefore, the concept of a carer's assessment holds little, if any, meaning. The purpose and function of the adult, social-care system lacks clarity, and carers are not aware of their rights to support, or they gain support from alternative sources, such as family/friends, or third-sector organisations. Moreover, that the majority who are assessed receive advice and information only suggests that either their needs are such that a PB is not required, or that the offer of one is declined, or is not seen as appealing, or that there are issues with the assessment process, and it is not capturing the real extent of need that exists.

However, as indicated in the limitation sections above, given the very small effect size in the modelling strategy used in this analysis, caution must be used in drawing conclusions beyond the sample. This indicates that many other factors shape a carer's wellbeing.

Moreover, quantitative analysis cannot explain why PBs may not improve carer wellbeing, or why so few carers are known and assessed by CASSRs. Exploring with carers themselves, their experiences of the assessment-and-support-planning process, has the potential to address the questions posed by this secondary analysis of national performance and survey data. Phase three of the study now moves on to explore carer experiences of PBs and begins with a narrative synthesis of the literature on PBs and its relationship with carer wellbeing.

Chapter 7 – Phase three - Carer Experiences of Personal Budgets: A Qualitative Study

7.1 Introduction

This chapter deals with phase three of this thesis, which sets out to explore what effect, if any the policy intention to promote the wellbeing of carers through the administration of PBs was having in practice. This was achieved by exploring insights from carers themselves about the difference they felt PBs had made to their own lives. This final phase of the thesis sought to answer the third, and final, research question: ‘What difference has personal budgets made to carers’ lives?’

This was performed in two ways:

1) A narrative synthesis of the evidence base underpinning the efficacy of PBs on promoting carer wellbeing. The purpose for conducting a narrative synthesis was to explore if any of the issues identified in the genealogy of caring and wellbeing, presented in chapters four and five, were corroborated in the empirical literature. Three key issues were identified in the genealogical analysis. Firstly, that primary responsibility for the provision of care was framed at the level of the individual carer, rather than the government. Secondly, that carers are responsible for promoting their own wellbeing. Thirdly, that PBs cannot facilitate carers to have choice and control over their lives, and therefore, improved wellbeing because the circumstances of carers’ lives, such as socio-economic characteristics and gender, have a greater impact on wellbeing than PBs.
2) Semi-structured qualitative interviews (held between June to December 2018) with 17 carers, who received a PB to understand their impact and whether or not they promoted their wellbeing in the way that the Care Act (2014) intended.

7.2 The efficacy of PBs on improving carer wellbeing - A narrative review of the literature

7.2.1 Methodological approach to the review

The aim of this narrative review was to produce an authoritative synthesis of the underpinning evidence (including, but not limited to, primary research) of the efficacy of PBs on promoting carer wellbeing (Greenhalgh *et al.*, 2018). A preliminary synthesis provided a descriptive account of the key features, research design and results of included studies, to begin the process of identifying patterns of similarity, and differences, between studies – see table 13 on pages 181 to 192 (Popay, 2006). The synthesis aimed to address the third and final research question: 'What difference does PBs make to carers' lives?'

The review was systematic in nature, in that it approached the review process in a comprehensive, critical, and reproducible way, using structured-search criteria, and reporting conventions that allow readers to critically review the quality of the search conventions applied, and the tools used in order to critically apprise papers that met the inclusion criteria (Aveyard, 2010).

A first search of the literature was carried out in 2018. However, because of the paucity of evidence located, a second replica search was carried out in August 2020, applying the same search terms that were used in 2018. The only difference being that the search was widened to include research carried out from 2001 rather than 2014 (which was the start date of the first search). The reason for increasing the date range was to accommodate the effects of the 2000 Carers and Disabled Children Act, which gave LAs the power to provide support to carers in the form of DPs; and the 2004 Carers (Equal Opportunities) Act, which mandated LAs to consider a carer's wider need for employment, education, and leisure as part of the carer's assessment process. The reasoning for carrying out a second search was to capture any evidence of LAs that were using their powers under this Act to offer carers PBs before this became a legal requirement to do so, under the Care Act (2014). This wider date range was not included in the original search because it was anticipated that there may be sufficient literature on the effect of Care Act-specific carer PBs between the time period of 2014 to 2018, but this was not the case. The reason for allowing a two-year gap in searches, was to allow for studies that were being conducted, post implementation of the Care Act in 2015, that may have taken several years to navigate the journal-publication process to hopefully have made it to publication by 2020.

As a narrative synthesis review, no restriction was placed upon the type of study to be included. As Greenhalgh *et al.* (2018) argues, meaningful narrative syntheses draw upon a range of knowledge sources (not just academic databases) to reflect the complexities of topics being studied. Although narrative synthesis reviews diverge from the methodological approach adopted by formal systematic reviews, they are far from being unsystematic (Greenhalgh *et al.*, 2018). Indeed, a systematic approach to the identification of included papers was applied and is set out below for readers.

A structured search was conducted using the ECLIPSE, stepwise approach. This stands for Expectation, Client group, Location, Impact, Professionals and Service. STARTLITE complimented the search which specified the Sampling strategy, Types of study, Approaches, Range of years, Limits, Inclusion and exclusions, Terms used (for searching) and Electronic databases searched (Aveyard, 2010).

The ECLIPSE method is helpful for exploratory questions like mine where the emphasis is on finding relevant information, rather than a comparison of options, such as randomised controlled trials. ECLIPSE is a non-clinical reporting convention that allows researchers to structure research questions in a way that introduces systematicity into the process. Each letter of ECLIPSE represents a stage in the search process, as outlined in table three on the next page.

It also supports the researcher to carry out a thorough search because it encourages detailed thought of the search components (Booth, 2016; Wildridge and Bell, 2002).

7.2.1.1 Selection procedure

Any study, including qualitative, quantitative, and mixed-methods primary peer-reviewed research, and systematic reviews that assessed, measured, or evaluated the impact of PBs on adult carer wellbeing, caring for adults, was included. Grey literature was included in the search parameter. Types of interventions could include the benefits to carer wellbeing of service-user-specific PBs, as well as the impact of carer-specific PBs on their wellbeing. Table 10 below provides a summary of how ECLIPSE was used to structure the literature search; and table 11 on page 170 shows the search terms used to define the search strategy.

7.2.1.2 Search methods

Table 10. Using ECLIPSE to structure the search.

Expectations	*Improved levels of social participation and inclusion, Improved levels of health, wellbeing, and life satisfaction.*
Client group	*All adult carers in England*
Location	*Community setting*
Impact	*Increased numbers of carers receiving carer' assessments and PBs. PBs leading to self-reported improved levels of subjective wellbeing. Carers reporting increased choice, control, and ability to participate in society economically and socially as a result of receiving a PB.*
Professionals	*Social Workers and other designated workers carrying out assessment and support planning functions on behalf of a public body (Local Authority)*
Service	*Local Authority Adult Social Care Departments with CASSR responsibility*

STARLITE complemented the structured nature of ECLIPSE, because it introduced another layer of systematicity. It defined the search strategy and created a boundary around the literature review (Aveyard, 2010). For instance, I carried out a comprehensive sampling strategy to search for any qualitative, quantitative, or mixed-peer-reviewed research, and systematic review that identified, measured, assessed, or evaluated the efficacy of PBs on promoting carer wellbeing. I also used a snowballing strategy to search the bibliographies of papers that met the inclusion criteria – see table 13 on page 173.

Table 11. Using Starlite to structure the search.

Sampling strategy	***Comprehensive***
Type of studies	*Any kind of qualitative, quantitative, or mixed-primary peer-reviewed research and systematic reviews that report on the efficacy of PBs on promoting carer wellbeing.*
Approaches	*Electronic database search, Subject search; snowballing; internet searching (organisational research and social-work-specific sites (Social Care Institute for Excellence (SCIE) and Research in Practice for Adults (RiPFA)).*
Range of years (start date – end date)	*Applied a start date of 2001 to reflect the date at which PBs for carers became a power LAs could exercise. No end date limiter.*
Limits	*English; human; adult over 18 years (Care Act applies to adults caring for adults only and England-specific statute), peer-reviewed, full text.*
Inclusions and exclusions	***Exclusion**: Adults caring for children and children caring for adults. Studies that do not relate to PBs promoting carer wellbeing and/or participation and inclusion in society. Papers that relate to PBs and their delivery outside of England. Papers that relate to the impact of PBs on the cared-for person and exclude the carer's experience.* ***Inclusion**: Any paper that meets the aim and focus of the study. For example, papers that identify, measure, or evaluate the role of PBs in promoting carer wellbeing, participation and/or involvement in society. Papers that discuss the effectiveness of the Care Act (2014) in promoting carer wellbeing. Papers that discuss factors that affect the participation and inclusion of carers in society. Papers that discuss/evaluate the impact of PBs on carers' lives.*
Terms used	*"caregiver*" or "informal carer*" or "informal caring" or "caring" or "carer" AND "carer stress" or "carer burden" or "carer impact" AND "personal budget" or "direct payment" or "personalisation" AND "inclusion" or "include" or "participation" or "involve*" AND "wellbeing" or "well-being" or "social" or "economic" AND "Care Act 2014" or "Care Act"*
Electronic sources	*CINAHL complete, Medline, EJournals, PsychARTICLES, PsychINFO, Community Care Inform, Social Care Online (produced by SCIE), Sage Journals, Jiscmail (carer research directory), RiPFA (research in practice for adults), JTSTOR, Google Scholar, Scopus, Web of Science, Science Direct, Proquest dissertations.*

Electronic searches of research databases were carried out, as well as a search of the grey literature (including research reports produced by organisations such as Carers UK and The Carers Trust). Ebscohost was used to search CINAHL complete, Community Care Inform, Medline, PsychARTICLES, PsychINFO, Ejournals, ebooks, and Proquest dissertations as well as Web of Science, Scopus, and Sage journals. Other database searches included a Jiscmail carer-specific research directory, and RiPFA (research in practice for adults – social work specific educational website). Research repositories held by Carers UK and Carers Trust were also selected for this search. A further bibliographic search was conducted on papers of relevance (snowballing) (Aveyard, 2010).

Table 12. List of research databases searched and number of hits

Databases searched	**Number of 'hits'**	**Papers that met inclusion criteria**
CINAHL complete	20	2
Social Care Online (SCIE)	55	3
Medline	32	1
PsychARTICLES	8	0
PsychINFO	6	0
Ejournals	0	0
Proquest dissertations	10	0
Web of Science	24	1
Scopus	14	3
Sage journals	150	4
Jiscmail carer directory	55	1
RiPFA	8	0
Carers UK repository	3	1
Carers Trust	1	1
Snowballing	22	2

7.2.1.3 Data collection, extraction, and analysis

There were five stages to the review process. Guidance on the conduct of narrative synthesis from the ESRC Methods Programme by Popay (2006) was followed, although not all stages were relevant to this review. Stages that were not relevant were the development of a theory of change, and logic model chain, of causal assumptions, about how PBs promote carer wellbeing, for who and why. That is, because no a priori assumptions were made about the causal relationships between PB and wellbeing, before the study began. Each stage is outlined below:

Stage 1: Titles and abstracts were read and assessed for eligibility against the inclusion and exclusion criteria – see table 13. Full texts of potentially relevant papers were retrieved for full text review, where it was felt that insufficient information was given in the abstract to determine eligibility.

Stage 2: Full paper copies, where they were deemed to meet the inclusion criteria were examined, to determine if they did meet the inclusion criteria. One paper was rejected at this stage, from 19 selected.

Stage 3: Data were extracted from the selected papers in order to carry out a preliminary synthesis of included studies. This involved a textual description of each of the included study's characteristics, including their main findings and methodological approach. Data extracted included author(s), year, paper title, study population, research aims, study methods, results (grouped by recurring theme), and conclusions.

The preliminary synthesis can be seen in table 13 (starting p181.). Creating a summary table was a helpful tool in beginning to identify patterns of similarity and difference, about the efficacy of PBs on promoting carer wellbeing within and between included papers. (Popay, 2006).

Stage 4: Assessment of the quality of included papers was appraised using the Critical Appraisal Skills Programme (CASP) for quantitative and qualitative studies. No included studies were excluded on the basis of their quality appraisal. Rather, the results of the narrative review (section 7.2.2.3 below) synthesise the thematised findings in relation to their robustness and trustworthiness, in drawing findings from their analysis. For example, some studies did not describe their methods in detail (Larkin, 2011), while others (Mitchell *et al.*, 2014) failed to explain why participants were given a choice over whether to attend focus groups or individual interview, when both have data quality advantages and disadvantages. Some studies were practice reports or organisational reports (Bennett, 2016; Dittrich, 2013), therefore, do not conform to the rigours of academic research in terms of being explicit on methodology or design bias. These and other issues of rigour and trustworthiness are discussed in relation to the voracity of findings and conclusions drawn by paper authors.

Stage 5: The primary analysis was an assessment of the way in which the evidence base determined that PBs promoted carer wellbeing, by grouping included study findings by commonality of theme.

7.2.2 Results

7.2.2.1 Description of included studies

Quantitative, qualitative primary research and/or mixed studies addressing the research question (at the time at which the first search was carried out in June 2018) found 10 papers, of which one, specifically, examined the efficacy of PBs on promoting carer wellbeing. That was a report, produced by the Carers Trust in 2016, which conducted an online qualitative survey on the impact of the changes brought about by the Care Act (2014) for carers, including the provision of support through PBs. The remaining nine papers focused on two key areas of knowledge. One was the impact on wellbeing (benefits and challenges) for carers when they were managing another person’s PB on their behalf. For example, where the person being cared for lacked the mental capacity to manage their own budget. The second, was the impact of the service user’s PB, and how that may indirectly support the carer’s wellbeing to be able to have a life of their own.

The additional search in 2020 yielded eight new papers (that met the inclusion criteria): one paper that specifically explored how LAs assessed and supported carers since the introduction of the Care Act (2014) (Mitchell and Glendinning, 2017): and two, that examined the impact of carer-specific budges on carers’ lives and their wellbeing (Dittrich, 2013; Moule *et al.*, 2014). The remaining five papers focused on the impact of service-user PBs on carers’ lives, as did papers in the original 2018 search. All included studies related to adults caring for adults in England, which is the criteria laid out in the Care Act for access to PBs.

Out of the 18 included papers, one carried out a quantitative randomised controlled trial (RCT) (Jones *et al.*, 2014). Three papers reviewed the literature (Arksey and Glendinning, 2007; Larkin, 2011; Larkin and Mitchell, 2015). Two studies carried out mixed-methods research (Moran *et al.*, 2011; Woolham *et al.*, 2018). The remaining 12 studies all carried out qualitative primary research to explore the impact of PBs on carers’ lives.

From the preliminary synthesis of included papers, discernible patterns were identified in relation to factors that influence the efficacy of PBs on promoting carer wellbeing. These were: 1) The degree to which carers were able to exercise choice and control over how their PB was spent. 2) Professional practices, such as the way in which carers were assessed for eligibility for PBs; and 3) Organisational practices – the ways in which LAs worked which both acted as facilitators and barriers to the way in which PBs supported carer wellbeing.

Relationships between the included studies and explanations for the patterns of similarity and difference identified are synthesised thematically in section 7.2.2.3 ‘Results of the synthesis’.

Table 13. Summary of relevant findings from the literature.

Author, Year & Journal article	Research aims and methods	Thematised relevant findings
Mitchell, W. and Glendinning, (2017) **Allocating Personal Budgets/Grants to carers**	A qualitative (multi-methods) exploratory study of how LAs assess and allocate support to carers since the introduction of the Care Act (2014) Qualitative survey findings thematically analysed and used to inform follow up semi-structured interviews with LA carer lead officers.	• Significant variation in how PBs are allocated to carers with no consistency across England in how the national eligibility criteria is interpreted. • Support to carers tends to be defined in relation to their caring role rather than broader life opportunities, such as employment and education.
Jones, K. et al (2012) **Can Individual budgets have an impact on carers and the caring role?**	A quantitative study examining if individual budgets (IB) have an impact on carers and the caring role. To analyse whether caring for someone who receives a PB improves carer participation and wellbeing. Carers randomly sampled from pre-existing RCT study where PBs were piloted in 13 CASSRs; and allocated to intervention (IB) and control groups (commissioned service).	Findings broadly support the hypothesis that service user individual budgets can indirectly benefit the carer. Carers in the intervention group (IB group) reported better quality of life scores (mean 4.72, $p<0.05$) compared to the control group (commissioned services) 4.25. Carers reported improved subjective wellbeing scores compared with carers in the control group, but this was not statistically significant ($p=0.18$). However, there were some examples were caring for someone with an IB contributed to greater stress. For example, carers in the IB (intervention group) spent more time caring compared with carers in the comparison group. Administrative management of the budget was cited as one example of this.
Mitchell, W.; Brooks, J. and Glendinning, C. (2014) **Carers Roles in Personal Budgets: Tensions and Dilemmas in Front Line Practice.**	A qualitative study exploring how practitioners recognise and balance the needs and interests of service users and carers. Reports findings from nine qualitative focus groups, (n=47) carried out with practitioners involved in service user and carer assessments working in older people's and Learning Disability social work teams.	Findings show that practice tends to focus on the service user assessment to the exclusion of the carer's needs, despite practitioners describing how carers needs can be addressed adequately through a comprehensive service user assessment. Variation in practices identified between the two teams. Longevity of relationship between practitioners and adults with LD and their families was seen as an important factor in being able to balance service user and carer needs. Practitioners ambivalent about the benefit and value of carers' assessments because they could raise unrealistic expectations on the part of the carer.
Woolham, J.; Steils, N.; Daly, G. and Ritters, K. (2016).	Mixed methods study assessing the impact of PBs on unpaid carers of older people. Comparison of carer stress between carers of people with PBs and those with a managed PB (MPB).	Findings show positive and negative effects of service user PBs. Positives reported greater flexibility for carers, such as arranging paid carers at times that suited the family rather than the service provider.

The impact of Personal Budgets on Unpaid Carers of Older People.	Postal survey (n=1500) of carers of older people who received either a PB or MPB in 3 LA areas with follow up semi-structured interviews (n=31).	Negatives include administrative burden of managing the service user PB causing anxiety for some carers. More carers reported providing more care where the older person had a DP compared with the MPB group. The Zarit care giver burden scale (Zarit, et al., 1989) used to measure stress. More carers of DP users experienced moderate to severe burden compared with carers of MPB users (not statistically significant).
Seddon. D and Robinson, C. (2015) **Carers Assessments: Continuing Tensions and Dilemmas for Social Care Practice.**	Longitudinal qualitative study exploring tensions and dilemmas in carers' assessments for social care practitioners. Qualitative analysis of 383 in depth interviews with practitioners drawn from 20 LAs over a 20-year period across England and Wales (1993-2013).	Authors report long standing ambivalence to the carer's assessment process. Practitioners reluctant to use the terms carer and assessment because of its exclusionary and deficits focus. People do not identify with the term carer and assessment comes across as a test of capacity rather than needs led. Assumptions about willingness and ability to care continue to be made despite legislative reform. Carers' assessments are not linked to the service user assessment when carried out separately and so miss the reciprocal nature of the couple relationship. Recommendations that assessments should adopt a narrative focus that consider the future and carers' aspirations for their own lives in terms of career/educational aspirations.
Dittrich, R. (2013) **Innovative use of Carers Direct Payments**	Good practice guide for commissioners and carers lead officers on facilitating use of regular and one-off carer direct payments.	Impact report shows that delivery of carer specific PBs that move away from traditional ideas of breaks and respite care can have a positive effect on carer health and wellbeing. Examples cited as innovative practice include using PBs to pay for art classes, driving lessons or holidays.
Moule, P., Pollard, K., Clarke, J., Lawson, B., Fear, C., Thompson, R. and Young, P. (2014) **An integrated approach for individualised support: Carers views**	Qualitative (thematic) analysis of 40 semi-structured interviews exploring the views of carers receiving a one-off cash payment. Part of a wider service evaluation of an integrated health and social care assessment and support team.	Findings suggest that one off payments have positive effects on carer health and wellbeing broadly. However, very limited information provided on specific benefits in the paper makes it is difficult to draw conclusions. Positive comments included the freedom of choice which was appreciated by 25 respondents. Some respondents reported mixed emotions such as feelings of 'cheating'; being given money of their own to spend while others felt they were entitled to the payment.
Larkin, M. (2015) **Developing the knowledge base about carers and personalisation:**	Qualitative thematic analysis of 23 semi-structured interviews with couple carers across 11 English LAs to explore the carer service user relationship when a service user moves from a managed service to a personal budget.	Thematic analysis of interview data shows both positive and negative effects of moving from a managed service to a personal budget.

contributions made by an exploration of carers perspectives on personal budgets and the carer-service user relationship		75% of respondents reported positive effects including: • Improved relations between carer and cared for. Reasons cited are having more choice over how care is sought made carers feel happier and carer and service user 'less snappy' with one another. • PBs paid for activities that couples could take part in together whereas managed service tended to focus solely on the service user's needs. • Four respondents were employed by the service user as their paid carer which increased flexibility and trust in the caring relationship. • Others reported that a PB had enabled them to spend time apart which the previous method had not. And pick up hobbies and outside interests that the carer had lost touch with because of caring. Two thirds of respondents reported negative effects including: • Lengthy and time-consuming administration of PB, examples cited: staff recruitment, managing holiday, sickness, and performance issues. • 50% reported stressful encounters with LAs, example cited: lengthy wait times for assessment or reassessment (when circumstances change) and disputes over sufficiency of PB to meet assessed need.
Moran, N., Arksey, H., Glendinning, C., Jones, K., Netten, A. and Rabiee, P. (2012) **Personalisation and Carers: Whose Rights? Whose Benefits?**	Mixed methods national evaluation of the impact and outcome of a pilot site cash for care individual budget schemes (IBs) for carers compared with carers of people in receipt of managed services in England between 2005 and 2007. Three staged study comparing impact by: 1. RCT – intervention study with carers allocated between IB experimental group and MPB control group (n=1000) 2. Quantitative analysis of structured interviews with carers sampled from the RCT and IB and Carers Lead officers (n=130)	• Quantitative findings suggest that carers of people in the IB group were more likely to report higher scores on the single QoL measure (mean 4.27; $p<0.05$) compared with carers of people receiving a managed service (mean 4.25; $p<0.05$). Positive correlations identified in other outcome measures with 38% of carers in the experimental (IB) group reporting they were fully occupied in activities of their choice compared with 20% in the control group. Carers of older people more likely to report (50%) they had no outstanding needs for social participation and involvement compared with carers of people with a learning disability. • Qualitative findings indicate that IBs have both positive and negative effects upon carers. Positive impacts include greater choice over how they spend their free time and negatives reported in relation to the administration burden of managing the IB.

	Qualitative analysis of semi-structured interviews with a sub-sample of carers (n=24) from structured interviews (older people and Learning disability carers only)	
Glendinning, C., Mitchell, W., and Brooks, J. (2015) **Ambiguity in practice? Carers' roles in personalised social care in England**	Qualitative study exploring the roles played by carers in service user PBs. Thematic analysis of 14 dyadic interviews with older and learning-disabled service users, and their carers, complemented a survey carried out with practitioners and senior managers in LAs.	• Findings suggest that carers play an important role in the service user assessment and support plan, but carers are less likely to receive an assessment and support plan themselves. • Service user PBs were seen to benefit the carer but these benefits did not reflect policy intentions that practice should aim to enhance carer choice and control over their lives.
Larkin, M., and Dickinson, H. (2011) **Personalisation: What Will the Impacts Be for Carers?**	Working paper examining the literature to assess the impact of personalisation on carers. There is a focus on what third-sector organisations can do to maximise the impact of personalisation for carers.	The paper presents a mixed review of both positive and negative effects of personalisation on carers' lives. • Positive effects are reported in the way that carers can exercise greater choice and control over their lives, such as improved relationships, and feeling more involved in care planning conversations. • Negative effects – carers' capacity to undertake paid work as a result of PBs not evidenced to have increased.
Mitchell, W. and Glendinning, C. (2015) **How do Local Authorities Allocate Resources to Carers through Carer Personal Budgets?**	Qualitative survey and interviews. Key aims of the study were to explore: • What approaches local authorities in England were using to determine eligibility for, and levels of, carer PBs. • Why these approaches were used. • Anticipated changes to these approaches following implementation of the Care Act (the study was conducted before the Care Bill received Royal Assent). Online survey distributed to Carers Lead Officers in 30 LAs and follow-up telephone interviews with sub-sample (n=20) of carers lead officers.	• Variation exists in how carer eligibility is determined for the purposes of PB • Assessments are more likely to be carried separately than jointly with the cared for, and, therefore, less likely to take account of carers broader life opportunities. • Determination on the level of the PB varies between LA with payments ranging from £60 to £300 per year. Administration methods vary between annual and monthly payments.
Rand, S., and Malley, J. (2014)	Qualitative study exploring carers' experiences and perceptions of their quality of life with and	• The wellbeing and support provided to the cared for impacts the carers QoL

Carer's quality of life and experiences of adult social care support in England.	without adult social care support either for themselves or the person they care for.	• Barriers to accessing social care support impact on carer QoL. Difficult to navigate complex system, unresponsive and defensive staff, and lack of transparency over what might be offered following assessment affect carer QoL emotional wellbeing.
Bennett (2016) **The Care Act (2014) One year on – The Carers Trust**	Report into the impact of the Care Act for carers one year on. Data collected via online survey and three evidence gathering days held in different regions of England. The report asked, 'Have carers noticed any difference since the Care Act came in?'	• The report finds that carers have not noticed any difference since the introduction of the Care Act (2014). • In relation to PBs, survey findings suggest that carers who were offered support were given 'supply led' rather than 'needs led' responses. PBs were either one off 'one size fits all' responses to carers assessments, rather than individualised/personalised responses to carer circumstances.
Carers UK (2008) **Choice or Chore? Carers Experiences of Direct Payments**	Survey reporting on carers experiences of being involved in the DP of the person being cared for.	• Survey findings present a mixed picture with both positive and negative impacts reported. Just under half (46%) of respondents report the person they look after being able to purchase things not available through the LA, and 49% report improved continuity of staff, being able to recruit and pay the same carer to provide support to the cared for. • Negative effects are reported in the administrative burdens accompanying the DP process. There were 21% of respondents who reported less free time as a result of the administrative burdens associated with managing a DP and 10% spent between 6 and 15 hours per week on managing the DP.
Brooks, J., Mitchell, W., Glendinning, C. (2016) **Personalisation, Personal Budgets and Family Carers: Whose Assessment? Whose Budget?**	Qualitative study aiming to: • Describe social care practice in relation to carers' roles in personalisation processes. • Examine how far these processes appear to recognise and balance the needs and wishes of service users and their carers. • Explore what roles service users and carers want carers to play in personalisation processes. Postal survey of 16 Adult Social Care Departments in 2 English Regions with follow up interviews with a sub-sample of carers lead officers.	• Findings suggest significant variation in 'personalisation processes' (assessment and support planning practice) between CASSRs. • Respondents reported that carers are routinely involved in discussions and decisions about the care and their own contribution. However, less often, carers own needs were not considered as part of the service user assessment. Survey respondents reported ambivalence towards the purpose and value of separate assessments of need for carers. The resource value of carers was recognised in that any help given by carers reduced the level of the service users PB, and, therefore, saved the CASSRs money.

Larkin, M., and Mitchell, W. (2016) **Carers, Choice and Personalisation: What do we know?**	Review of empirical literature about what is known about the relationship between personalisation and carers.	• Findings reported in relation to six themes: 1)The concept of choice; 2) the complexity of choice for carers; 3) choice for carers in late modern society; 4) personalisation and choice; 5) existing knowledge about carers; and 6) factors influencing carer choice. • The relationship between personalisation and caring is an under-researched area. Review, highlights the paradoxical nature of framing personalisation for carers in relation to choice and control, because theories of personalisation can simultaneously enable and constrain carers' lives.
Baxter, K., and Glendinning, C. (2013) **The role of emotions in the process of making choices about welfare services: the experiences of disabled people in England.**	Longitudinal qualitative study (2007-2010) exploring the role of emotions in the process of making choices about health and welfare. 55 adults with disabilities and ill health purposively sampled from voluntary organisations, health services, and LAs. Qualitative interviews carried out annually and analysed using Ritchie and Spencer (1994) Framework Approach.	• All participants reported an emotional response while making choices about their health and welfare. • Negative responses ranged from fear, anxiety, stress, anger, and isolation. Some positive emotions were expressed in relation to excitement and hope, but these were in the minority. • Fear of the unknown, reduced physical and mental wellbeing, and fear over losing independence were of great concern to participants. • Impact of making a choice was seen to be emotionally draining and feeling overwhelmed at making the right choice.
Arksey, H., and Glendinning, C. (2007) **Choice in the context of informal care giving**	A literature review about carer choice situations from 1985 to 2006.	• The review highlighted the problematic nature of choice making for carers. Choice is mediated by factors such as the relationship with the cared-for person, access to formal care and support services, and wider organisational and contextual factors that may be beyond the control of the carer.

7.2.2.3 Results of the synthesis

What stands out from the review is that there is no clear consensus on the efficacy of PBs on promoting carer wellbeing. All the included papers, except for Seddon and Robinson (2015), adopt a cross-sectional design. This takes a one off, snap-shot view of the efficacy of PBs on promoting wellbeing, and therefore, limits the interpretation of results because they do not take account of the effect of time on carer wellbeing, such as the impact of the ageing process on carer wellbeing. It has already been established in the genealogy of wellbeing, in chapter five, that wellbeing can be conceived of as a dynamic, fluid state, shifting over time in response to different life circumstances (Bache *et al.*, 2016; Scott, 2012). The effect of time has been reported to have a materially important effect on a carer's wellbeing, and their ability to participate in economic and social life (Carmichael and Ercolani, 2016; Garlo *et al.*, 2010; Henz, 2006; Lin *et al.*, 2012). Therefore, one can challenge the claims in papers adopting a cross-sectional design that argue PBs promote carer wellbeing because of their single point in time view of impact.

Whether a study reports on the impact of carer specific PBs, or the impact of service user PBs upon carers, the findings are equivocal. What is evident, is a dichotomous split between two groups of papers. One group of studies suggests that PBs (either directly or indirectly delivered to carers) do promote wellbeing, because of the degree of choice and control that carers can exercise over their lives, such as increased autonomy and decision-making, or being able to choose what to do with free time created by a PB (Dittrich, 2013; Jones *et al.*, 2014; Larkin, 2015; Larkin, 2011; Moran *et al.*, 2011; Moule *et al.*, 2014). This is contrasted with a second group of included papers that argue that PBs do not promote wellbeing, because they reduce the choice and control that carers have, citing the administrative burdens associated with the management of PBs as a key reason why (Brooks *et al.*, 2017; Glendinning *et al.*, 2015; Mitchell *et al.*, 2014; Seddon and Robinson, 2015).

What is interesting about this split is that the papers discussing the barriers to carer wellbeing, in terms of economic and social participation, were also those that interviewed the service user as part of the study's design. In particular, Jones *et al.* (2014); Mitchell *et al.* (2014); Seddon and Robinson (2015) all reference the importance of a positive relationship between the carer and cared for, and availability of care and support for the disabled or ill adult as important determiners of a carer's ability to participate in economic and social life. In contrast, studies that reported on the positive effects of PBs sampled carers only as their target population. This distinction introduces the concept of relationality and its role in shaping the degree to which carer wellbeing can be promoted, when it is conceived of in relation to carers being able to exercise choice and control over their own lives.

Consideration of relational factors, and how they influence the extent to which PBs can promote carer wellbeing and participation, is another theme identified alongside choice and control. The relational aspects of caring are a theme picked up in several studies but particularly the papers that carried out literature reviews (Arksey and Glendinning, 2007; Larkin and Mitchell, 2015). Both reviews challenge the assumptive nature of choice conceptually, and Larkin and Mitchell (2015) suggest that the logic of personalisation being extended to carers masks the structural inequalities that have a broader influence on the extent to which carers can exercise choice and control, rather than a PB being able to influence autonomy. Arksey and Glendinning (2007) conclude that factors often beyond the carers control shape the degree to which they can choose how they live their lives, such as the nature of the relationship with the cared for, availability and affordability of paid care, and wider contextual factors such as organisational and professional practices that all play a role. These findings are reinforced by those in the introductory chapter, where the heterogeneous nature of the caring population is identified as a factor in a carer's ability to participate in economic and social life (Al-Janabi *et al.*, 2018; Arber and Ginn, 1992; Dalley, 1996; Roth *et* *al.*, 2009; Verbakel *et al.*, 2017). The effect of caring impacts different carers differently. This finding is corroborated by the Rand and Malley (2014) study whose qualitative survey, with follow up interviews with a sub sample (n=31), found that carers experiences of their QoL were strongly associated with the access to social care for the person they looked after. Levels of care and barriers to accessing care and support impacted upon carers’ emotional and physical wellbeing. A report produced by Carers UK (2018), on carers experiences of involvement in the DP of the cared for, found that 21% of respondents to their online survey had less free time since taking on a DP on behalf of the person they cared for. These overall findings from the literature have been condensed into the three following themes: 1) Choice, control, and relationality; 2) Professional practices; and 3) Organisational practices. It is within the overview of themes discussed in the section below that the trustworthiness and validity of studies is discussed.

7.2.3 Choice, control, and relationality

Within the parameters of this narrative synthesis of the literature, two broad groups are reported in relation to the efficacy of PBs on promoting carer wellbeing. One group who argue that PBs promote wellbeing because they increase carer choice and control. This occurs because PBs increase flexibility, giving carers greater freedom and ability to do things that they want to (Dittrich, 2013; Larkin and Mitchell, 2015; Moran *et al.*, 2011; Moule *et al.*, 2014; Woolham *et al.*, 2018). PBs are conceived of as levers that support independence and autonomy for the carer. Evidence to support this comes from participant self-reports: such as being able to employ a paid carer to come at a time that suits the carer, rather than the agency; or being able to pay someone the family knows and trusts to replace the family carer (Glendinning, 2008; Larkin and Mitchell, 2015; Moran *et al.*, 2011; Moule *et al.*, 2014).

However, what connects these papers in their findings is the narrow conceptions of choice of control being connotated with wellbeing and its relationship to the caring role. Having choice about the paid carer, who replaces you or being able to choose a family member to provide care for a short period while you take a respite break, does not acknowledge wellbeing in its broader conception in relation to any employment or educational needs the carer might have, which has been established already in both the genealogical analysis of wellbeing and WRP analysis of the Care Act guidance.

Study findings also raise methodological issues, for instance, in Jones *et al.* (2014) quantitative study, which carried out a randomised controlled trail (RCT), the study authors did not provide details of concealment. If study participants knew whether they were being allocated to the intervention group (receiving a PB) versus the control group who received a traditional commissioned service, then this could influence the study's findings and increase the risk of measurement error (Groves, 2009). This was also the case in the Moran *et al.* (2011) mixed-methods study which carried out an RCT in the first phase to evaluate the impact and outcome of a pilot site cash for care PBs scheme for carers. Findings suggested that carers of people in the intervention group who were receiving a PB were more likely to report higher scores on the quality-of-life measure (mean 4.27; $p<0.05$), compared with carers of people in receipt of a traditionally commissioned service. However, despite carers being randomly allocated to the control and intervention groups, the authors did not report whether participants and investigators were blind to the allocation process. If so, then the risk of selection bias increases as a result. Moreover, a pilot site evaluation may also be subject to possible 'pilot effects', because they are typically not thought of as being sufficiently extensive to provide conclusive results and conclusions that could be scalable.

The homogeneous nature of respondents in a number of studies reporting positive effects of PBs on wellbeing also increases the risk of bias. For example, in the (Jones *et al.*, 2014) study participants were overwhelmingly female (74%) and 26% male. The generalisability of their findings at a population level can be questioned given that men make up 42% of the caring population. Moreover, the study's random sampling of carers was skewed towards carers of people with learning disabilities (54%) with 26% of respondents looking after an older person and only 5% looking after someone with a mental health problem. There was no discussion of weighting measures being used to bring the sample ratios in line with population averages. This increases the risk of non-response bias if participants share more characteristics in common than they differ (Groves, 2009). This was also an issues with the Woolham *et al.* (2018) paper which carried out a mixed methods study assessing the impact of PBs on older people by comparing measures of stress using the Zarit care giver burden scale (Garlo *et al.*, 2010). Respondents to the stress survey who were allocated a PB were compared with respondents who received a traditional commissioned only service. However, there was significant variation in sample sizes between both groups. Carers of people with a DP (n=153) were significantly outweighed by people with a commissioned only service (n=1347). Thus, yielding direct comparison problematic because of the imbalance in sample sizes.

The second group of studies argue the reverse. That PBs provided either directly to the carer or indirectly to the service user in many ways reduce the choice and control that carers have over their lives because PBs can increase the workload for carers if they are managing the PB on behalf of the person they care for (Glendinning *et al.* (2015); Mitchell *et al.* (2014); Seddon and Robinson (2015). These included studies take a broader conceptual view of wellbeing compared to the first group in that choice and control are not connotated narrowly in relation to choices specific to the caring role. Mitchell *et al.* (2014) formed this view by carrying out a qualitative study exploring how practitioners recognise and balance the needs and interests of service users and carers. The sample was limited to practitioners in older adults and learning disability social work teams and therefore did not represent the views of practitioners in other social work teams, such as mental health and physical disability social work teams. The risk is that carers of people with mental health needs may have a qualitatively different experience to carers of older or learning-disabled adults. Moreover, context bias was not considered by the authors who carried out both one to one and group interviews and the evidence which suggests that people may position themselves differently in a group versus an individual situation (Ritchie *et al.*, 2014). Furthermore, in focus groups participants included both qualified a non-qualified practitioners. This may increase the risk of social desirability if non-qualified staff felt less empowered to be open in front of their more powerful qualified colleagues.

Some papers simultaneously report both positive and negative impacts of PBs on carers lives (Brooks *et al.* (2017); Jones *et al.* (2014); Larkin (2011); Woolham *et al.* (2018). These papers reflect the simultaneous and temporal experience that many carers face. Circumstances associated with caring can change on a daily basis and PBs in many of the studies report on the mechanistic way in which PBs are delivered which make it harder to measure or suggest that a PB alone can have a significant impact on a carer’s life. Mitchell and Glendinning (2017); Seddon and Robinson (2015); Woolham *et al.* (2018) found significant variation in how PBs are allocated to carers with no consistency in how the Care Act’s national eligibility criteria were being interpreted.

Support to carers tended to be defined in relation to their caring role rather than broader life opportunities such as employment and education. This is supported by Glendinning *et al.* (2015) who found that variations in assessment and support planning practices lead to inequities in that carers with similar needs were being treated very differently by LAs in their

PB allocation practices. Some LAs in the study graded carer eligibility based upon the number of hours of care being provided, while others graded risk as a determiner of eligibility, such as the risk of the caring role breaking down or risks to the carer's health deteriorating without support. This led to some carers in the study leading to far higher budget allocations compared to other carers. Even though the 2004 Carers Equal Opportunities Act made it a duty for public bodies to consider a carer's need for employment, education and training as part of the assessment process, Seddon and Robinson (2015) 20-year longitudinal study of social work practice in relation to carers' assessments and support showed that this what not routinely happening in practice.

One of the methodological challenges of studies like Mitchell and Glendinning's comparison of assessment practices between different LAs, is that LAs will vary in size, socio-demographic characteristics in population and comparator against indices of multiple deprivation. Therefore you are not always comparing LAs that are similar in size and context. Groves (2009) points out that when there is too much heterogeneity between samples, such as gender, age social class and so on it becomes more difficult to attribute how much the study's intervention is due to the outcome and how much can be explained by other factors, such as the sample characteristics themselves.

One example of the temporal experience of caring and the limited way in which carers' needs are defined is highlighted in Jones *et al.* (2014) where improved QoL scores for carers of people with a PB were offset by lower wellbeing scores compared with those caring for someone with a managed service. Similarly, no positive correlation was found between a PB and a carer's ability to participate in economic and social life. They conducted an RCT to test the hypothesis that service user PBs improve carer wellbeing and participation (n=959). Slightly more carers were in the control group (carers of people receiving a managed service, n=510) compared with the intervention group (carers of people receiving a PB, n= 449). This was followed up with structured outcome interviews with a sub-sample of participants selected from the RCT (n=129). Findings broadly supported their hypothesis because carers in the intervention group reported better quality of life scores (measured using an ESRC growing older research scale) compared with carers in the control group (those caring for someone who received a managed service, provided by the LA) (mean 4.72, $p<0.05$ compared with 4.25 respectively). Factors associated with having improved QoL were having a good relationship with the cared-for ($p<0.001$) and spending fewer hours caring for the service user ($p<0.05$).

However, a statistically significant association does not denote causation and not all findings were statistically significant. Carers in the control group reported better wellbeing scores (measured using a 12 item General Health Questionnaire (GHQ) scale) than those in the intervention group ($p=0.18$). So, carers who were not receiving a PB reported better wellbeing scores compared with those who received a traditionally managed service. Chi square tests of association were used to determine the relationship between PBs, and wellbeing and t-tests were used to examine mean differences in wellbeing scores between groups. These findings are corroborated by Rand and Malley (2014) whose qualitative study explored how carers experienced their QoL when either they or the person they cared for were supported by adult social care in England. Carers were recruited from a mix of LAs and carer specific voluntary organisations chosen to represent a cross section of LAs in terms of size, location, and population mix. The study recruited 31 carers in total who cared for family members with a range of conditions, including mental health problems (n=10); physical disability (n=14) and intellectual disability (n=6). They found that access to social care for the person they cared for had a significant impact on the carers QoL. QoL was measured in relation to six domains (occupation, control, social participation, self-care, time and space and safety). Other factors that affected the carers QoL included barriers experienced in accessing help and support. Findings suggested that adult social care was experienced as a complex system to navigate; staff could be unresponsive and defensive, and a lack of transparency was reported over what might be offered at the end of the assessment process. One of the limitations of this study is the small sample size and the fact that only three percent of sampled carers were looking after someone who was in receipt of an adult social care service. Therefore, the findings are limited to those participants who took part in the study. It makes it more difficult to state for example, that their findings could be applied to the broader eligible population because such a small number of adults were in receipt of an adult social care service.

One explanation for carers reporting lower wellbeing scores where they cared for someone with a PB compared to those who cared for someone receiving a traditionally managed service could lie in the examples cited by some papers where caring for someone with a PB contributed to greater stress for the carer. Administrative burden was cited in the Jones *et al.* (2014) paper by a number of participants and carers in the intervention group were found to be spending more time caring (mean, 81 hours per week) compared with 72 hours in the control group. There were no statistically significant findings of improved social care outcomes which were used to measure social participation; these were employment, control over daily life, personal safety, and level of carer support. Other factors that were positively correlated with better wellbeing scores were, not living in rented accommodation and caring not causing financial difficulties or difficulties in relationships with family members ($p<0.001$). So, although their research concludes that service user PBs indirectly provide positive outcomes for carers, their findings are limited. It cannot be stated with confidence that a PB alone contributes to better outcomes for carers. Particularly as those caring for someone with a PB reported lower wellbeing scores than those looking after someone receiving a managed service and on average provided a higher number of weekly care hours than those in the control group. One explanation for this could be the additional burden that participants associated with the PB that could be impacting their wellbeing scores. This raises questions over the degree to which there is consensus over the meaning of choice and the ways in which choice manifests.

Choice and control, in the context of personalisation connotes PBs with conceptions of freedom and autonomy. Carers can do what they want with their time away from caring, choice is framed within a context of rights-based language of autonomy (Duffy, 2010; Lymbery, 2012). However, rights-based language speaks to the rights of the individual and therefore it is challenging to consider the rights of carers in this context because of the relational nature of caring. For instance, the rights of the service user to exercise choice and control over their life may mean that decisions and choices they make may impact adversely on the carer's autonomy and freedom and vice versa.

Where papers suggest a positive relationship between PBs and subjective wellbeing and participation; constructions of wellbeing are narrowly defined. Positive outcomes for carers are associated with being able to have time away from their role, such as the service user PB enabling them to buy in replacement care at a time that suits the family (Jones *et al.*, 2014; Larkin, 2011; Woolham *et al.*, 2018). Or where the PB is directed at the carer. Examples of improved wellbeing are often described in relation to one off activities or purchases, such as relaxation classes, art classes or purchasing white goods (Dittrich, 2013; Moule *et al.*, 2014). Much like the examples given in the Care Act guidance on what a carer's PB could be spent on. An example of how a one off payment can support wellbeing is given by Dittrich (2013, p. 1) who defines a carers PB as one which enables the carer to do something beyond taking a break from their role. *"Something that makes an extra difference to them personally as an individual, e.g., art classes, driving lessons or assistance on holiday with the person they care for"*. Other papers reported being able to use a PB to pay for activities that couples could enjoy together. Larkin (2015) counters the traditional view that carers want to spend time away from the person they look after. Larkin interviewed couples and found that positive effects of PBs could be expressed in relation to couple activities.

What stands out from the literature review is that wellbeing or participation is rarely defined in relation to broader life opportunities, such as employment, training, and education. Only two papers specifically mention this. These are, Mitchell and Glendinning (2017) who found significant variation across England in how PBs for carers were defined and allocated and found no evidence from the qualitative survey and follow up interviews with Carers Lead officers that PBs were supporting carers back into employment, education or training. The second paper was Larkin (2011) who conducted a qualitative survey and follow up interviews with carers and found that a respondent's ability to undertake paid work was not increased as a result of receiving a carer PB.

Papers that argue PBs do not promote choice and control are framed from a range of perspectives, including their burdensome nature. Administrative burden is cited by a number of papers (Bennett, 2016; Brooks *et al.*, 2017; Jones *et al.*, 2014; Larkin, 2015; Mitchell *et al.*, 2014; Glendinning *et al.*, 2015; Moran *et al.*, 2011; Woolham *et al.*, 2018). Examples of burdens include recruitment and selection of paid care staff (when the carer is managing and/or involved in the service user's PB). Financial burdens are reported in relation to dealing with HMRC, employer responsibilities such as managing staff absence or paid carer performance. The idea of managing staff is cited by other papers in relation to the additional stress that carers may face if they lack confidence in the paid carer's ability to provide effective care, and/or they have to take time to train the paid carer in caring techniques, such as managing a colostomy or catheter care (Moran *et al.*, 2011; Woolham *et al.*, 2018).

Another perspective provided by the literature is that PBs can exacerbate the stresses and strains associated with a caring role because carers are now taking on tasks that were traditionally carried out by LAs, such as managing a PB on behalf of the service user (Arksey and Glendinning, 2007; Larkin, 2011; Woolham *et al.*, 2018; Mitchell and Glendinning, 2017). Other authors, Baxter and Glendinning (2013) suggest that choice may be avoided by carers because of the fears of potential conflict or negative consequences. They conducted a qualitative longitudinal study (2007 to 2010) exploring choice making in the context of changing circumstances. Psychological and behavioural economic theories of decision making were used to explore how individuals made health and welfare decisions. They found that all respondents (n=55) reported an emotional response while making choices and they were overwhelmingly negative emotions. They ranged from fear, isolation, stress, anxiety, and anger. Examples cited were fear of losing independence, anxiety and worry about making the wrong choice, for example whether to take a PB as a DP if the choice may lead to a negative outcome. Fear of the unknown was cited as reason against making a choice where the status quo was viewed as a safer less risky option.

Papers also reflected the complexity that exists in relation to the concept of choice. The extent to which carers can choose what they spend their budget on is mediated by the nature of their caring role and relationship with the person they look after (Glendinning *et al.*, 2015; Larkin, 2015; Rand and Malley, 2014). These papers describe both a symbiotic relationship between carer and cared for and one where tensions may be exhibited (Mitchell *et al.*, 2014). Tensions are evident in the studies that report carers feeling that they are still individuals with needs and aspirations, and this should not be forgotten by practitioners (Brooks *et al.*, 2017; Carers UK, 2018). Having said that papers that describe a symbiotic relationship in the main interviewed carers looking after their spouses. For example, the Larkin (2015) study thematically analysed interview data from 23 couple carers across 11 English LAs. Their findings of symbiosis are more likely to occur in couple carers compared perhaps with adult children caring for ageing parents therefore making it more difficult to extrapolate theories of symbiosis beyond the sample.

Relationships with paid carers and other professionals are given as another factor that influences the extent to which PBs support carers’ lives and allow them to exercise choice and control (Mitchell *et al.*, 2014). This was identified as another discrete theme titled ‘professional practices’.

7.2.4 Professional practices

One of the overriding factors (evidenced from the literature) that affects the degree of choice carers exercise is the attitude of practitioners towards the caring role (Larkin, 2015; Mitchell *et al.*, 2014; Seddon and Robinson, 2015). Mitchell *et al.* (2014) argues that carers continue to be marginalised in social care provision as practitioners continue to make assumptions about a carer’s willingness and ability to provide care. This is evidenced in papers that describe how carers contribution is routinely considered in the service user assessment but not the other way around (Brooks *et al.*, 2017; Glendinning *et al.*, 2015; Larkin, 2015; Mitchell *et al.*, 2014; Seddon and Robinson, 2015). What this means in practice is that outcomes defined during a separate carer’s assessments (carried out after the service user assessment and often at a later date) rarely (retrospectively) inform the service user assessment and decisions about the level of care and support provided to them. For example, a service user assessment may determine that a person has personal care needs that require support morning and evening seven days per week. Any care being provided by the carer will reduce the level of budget given to the cared for because it is no longer an unmet need. However, a later carer’s assessment may identify that a carer would like to get back into the labour market, but they cannot because of their caring responsibility. Technically this should prompt a reassessment of the service user’s needs but several papers suggest this would rarely if ever happen in practice (Mitchell *et al.*, 2014; Seddon and Robinson, 2015). One of the reasons cited for this can be found in the Seddon and Robinson paper where they carried out a longitudinal qualitative analysis over a 20-year period exploring tensions and dilemmas in carers’ assessments with social care practitioners. They found that practitioners often did not have sufficient time because of high caseloads to go back and carry out a separate carer’s assessment following the service user assessment of need. Therefore, the tendency was to complete an assessment of the carer’s needs as an integral part of the service user assessment. When this occurred, their analysis implies that carers’ needs tended to be considered only in relation to what they are willing and able to do in support of the service user and not what needs they have as an individual in their own right, such as work and social life.

These findings are corroborated in the Rand and Malley (2014) paper who found a lack of transparency over what might be offered at the end of the assessment process. Assessments tended not to evaluate the perspectives of both carer and cared for, even when joint assessments were carried out. Similarly Brooks *et al.* (2017) found that carers’ rights to assessment and support had been developed separately to the cared for therefore missing the interdependences that exist between carers and cared for needs. This was a finding from phase two of this thesis where secondary analysis of SALT and ASCOF performance data showed that carers who had their needs assessed alongside the person they cared for were less likely to receive a carer’s PB compared to carers who had a separate assessment of their needs.

Although the Seddon and Robinson study lasted for twenty years and therefore the longitudinal nature is able to capture change over time effects, there are some limitations because the researchers were not able to follow all social workers recruited when the study began in 1993. Practitioners taking part in repeated interviews represented 26% of the original sample size (n=98). This limits the validity of findings in presenting a longitudinal analysis for the whole sample.

Making assumptions about a carer's willingness and ability to provide care speaks to Twigg and Atkin (1994) typology of caring which identified how carers are often viewed as a resource by LAs. What they can contribute towards another's care, rather than being a person first and carer second. The effect of viewing carers through the lens of resource means that broader life opportunities continue not to be considered by practitioners because familial care is seen as the social norm and is therefore expected (Twigg and Atkin, 1994). It is this view of carers as resource that continues to dominate social care practice. Where carers' needs are routinely assessed within the service user assessment, the evidence suggests that they are also less likely to consider the carer's need for broader life opportunities, such as employment, education, and training (Mitchell *et al.*, 2014; Seddon and Robinson, 2015; Woolham *et al.*, 2018).

Practitioner perceptions of carers may also be influenced by the social work team they work in. Mitchell *et al.* (2014) used Ritchie and Spencer's Framework approach to qualitatively analyse data from nine focus groups in three CASSRs (n=47) comprising practitioners from older peoples' and learning disability social work teams. Findings suggest variation in practitioner practices between LAs and teams. Practitioners in learning disability teams reported that longevity of their relationship with carers as a factor in supporting carers to have a life of their own alongside caring. Longevity was associated with being able to develop trusting, open and honest dialogue between practitioners and carers. This was reported as especially beneficial where there may be conflict between the carer and service user. Whereas practitioners in the older peoples' teams more often had higher caseloads than learning disability social workers and therefore spent less time with carers and therefore were less likely to build long term relationships. This raises questions of equity of provision if inconsistent approaches are used by practitioners. This is supported by Glendinning *et al.* (2015) qualitative exploration of how LAs allocated resources to carers through PBs. They found significant variation between LAs and practitioners. Eligibility determination varied hugely with risk, carer health and the number of hours of care provided all being determiners of support in some areas.

Practitioner knowledge about the PB process is seen as another factor in the literature that may shape the extent to which PBs can promote carer wellbeing and participation. Woolham *et al.* (2018) carried out a mixed methods study randomly sampling (n=1500) carers of older people who received either a PB or managed PB (MPB) i.e., where the LA commissions the service on behalf of the individual. Their findings suggested that many carers felt poorly informed about the value and purpose of taking a PB as a DP and their role in administering it. Lack of information at the start of the assessment process and poor information sharing throughout the process between social workers and third-party brokers were cited by many. The sample sizes between the groups in the Woolham *et al.* (2018) study varied significantly. The sample for carers of people with a DP was (n=153) compared with (n=1,347) for people with an MPB. This variation in sample size increases the risk of bias in relation to measurement error because the difference in size renders the sample incomparable.

Having said that this finding is supported by the Carers Trust's report into the Care Act (2014) one year on (Bennett, 2016). They conducted an online survey with carers, practitioners, and carers' groups to answer the question '*have carers noticed any difference since the Care Act came in?*' The answer they reported was '*not yet'*. Reasons for this included patchy practitioner knowledge of carers' rights to support. Some practitioner respondents wrongly reported they thought that carer eligibility depended upon the cared for person's eligibility for support. From carers who completed surveys, 69% reported they had not noticed a difference since the Act's introduction and 65% had not received a carer's assessment. Of those who did receive a PB, many (figure not reported in the survey) reported that supply rather than needs led assessments were being conducted and PBs were being delivered either as a one-off payment and/or one size fits all approach. The report from the Carers Trust did not offer any detail on their methodological approach therefore it was not possible to question the validity of their findings.

7.2.5 Organisational practices and processes

The literature identifies other factors that influence the extent to which a PB can promote a carer’s wellbeing and the difference it can make to their lives. These can be described as organisational practices and processes because they reflect how bureaucratic mechanisms can hinder the difference a PB makes and the extent to which PBs cam improve the quality of a carer’s life. Seddon and Robinson’s 20-year longitudinal study (n=383) is a good example of this where they describe how assessment processes are not sufficiently dynamic enough because they do not take account of the reciprocal and temporal nature of the caring role on carers’ broader life opportunities. Practitioners interviewed over time reported frustrations at assessment forms that limited what could be recorded about the impact of caring on the carer’s life. One example given was a service user assessment that only recorded what the carer was willing and able to do for the adult in need of care and support. Practitioners described having to adapt forms to adequately reflect the impact that caring was having on individual lives. This is corroborated in Brooks *et al.* (2017); Mitchell *et al.* (2014). In Mitchell *et al*., (2014) nine focus groups with practitioners were thematically analysed. Several practitioners questioned the value of carers’ assessments because they felt they could raise expectations that could not be met. Assessment forms that encourage a narrative approach were cited as something that may benefit future practice with carers. This is corroborated by findings in the Brooks *et al.* (2017) and Rand and Malley (2014) studies where practitioners reported how they relied on the carer's provision of care because of an insufficiency in adult social care funding and availability of paid care. It is worthy of note however, that the risk of context bias increases with the use of focus group to collect data. It is known that research participants position themselves differently and therefore may give a different account of themselves than they might in a one-to-one interview situation (Ritchie *et al.*, 2014). As previously mentioned, focus groups also contained a mix of qualified and non-qualified staff which may affect the trustworthiness of the collected data. The authors do not mention the potential power imbalance that may exist within groups and therefore impact on the quality of data collected as a consequence.

How LAs administer their PB schemes is another example of a practice and process that is associated with the degree to which PBs can promote the participation of carers in society. Bennett (2016) and Mitchell and Glendinning (2017) indicate that practices and processes tend to deliver PBs in a mechanistic, one size fits all way. The ability for carers to have any choice and control over what they spend their PB on is shaped by the way in which their LA interprets the purpose and function of PBs; the availability of resources and decisions made about the amount of money that will be allocated to carer PBs alongside the availability of care and support to the adult with care and support needs. This was particularly the case in the Rand and Malley (2014) study which used extracts from interview data as supporting evidence of Klein *et al.* (1996) typology of rationing. Klein devised a model to describe six ways in which rationing occurs. 1) Rationing by deterrence – access is made difficult: *"We needed to [make adaptations around the home] and again I tried to phone social services and I just couldn't get an appointment, so I gave up".* 2) Rationing by denial – services are denied to specific individuals or groups because they are found to be ineligible, 3) Rationing by delay – access is discouraged by delay, 4) Rationing by deflection – agencies protect resources by channelling clients to other services, 5) Rationing by charging – the service user contributes towards the cost of the services they receive, 6) Rationing by termination or dilution - services are withdrawn or the quality or quantity of services is reduced (Klein et al., 1996).

The review of the empirical literature shows how concepts of choice and control are mediated by a range of factors which were thematically discussed as: 1) Choice, control, and relationality; 2) professional practices and 3) organizational practices. It is possible to summarise these factors at a micro and meso level.

At the micro level we have seen how individual circumstances such as the nature of the relationship between the carer and cared for is instrumental in the extent to which carers are able to exercise individual autonomy and choice. The relational nature of caring has shown the significance of the interdependency that exists between the needs and choices of one impacting upon the other, particularly in couple relationships. Such that consideration of choice and control from rights based self-determinative arguments may not always be usefully applied in the context of caring. Individual level assessment practices have been shown to affect the extent to which PBs can promote wellbeing, quality of life, and control for the carer. Practitioners continue to make assumptions about a carer’s willingness, and ability to provide care and joint assessments between the service user and carer rarely take account of carers needs for employment, education, and leisure. These individual assessment practices are in turn shaped by the organisations in which practitioners operate.

At the meso level the evidence points to effect of organisational practices on carers’ abilities to participate in economic and social life. Variation in how LAs interpret eligibility and administer PBs leads to inequity of provision with carers with similar levels of need receiving very different PB allocations from councils. Similarly, the sufficiency and access to social care for the person looked after has been shown to have a significant impact on a carer’s ability to have a life of their own whilst caring. There is a tendency for PBs to be viewed as a one-off payment and this is problematic because it takes no account of the temporal and relational nature of the caring role.

7.3 Summary

The literature review and preceding chapters demonstrate that there is no real consensus in research and policy terms about the value and effectiveness of PBs in giving carers greater choice and control, and therefore autonomy over their own lives, such as access to employment, education and leisure or reducing their caring roles. Indeed, it is questionable whether PBs as a policy lever have any materially positive effect on promoting carer wellbeing when the evidence presented in preceding chapters suggests that socio-demographic characteristics, such as income and social class; the nature of the relationship between carer and cared for, and the availability and affordability of services to support the cared-for are more likely to promote carer participation and inclusion (and therefore wellbeing) than a PB. Evidence in support of the positive benefits of PBs takes a narrowly defined view of wellbeing and does not take account of carers' needs for broader life opportunities.

One of the issues that the literature has thrown up is the way in which the personalisation agenda has operated at the individual, rather than family level. PBs are either delivered to the service user and/or the carer separately with no acknowledgement that a PB given to one party may reduce and affect the choices and control of the other. The administrative burden of managing a PB, leading to an increase in the amount of time caring is one example of this identified in the literature. Individually delivered and administered PBs to service users, and carers take no account of the interdependent and reciprocal way in which families lives connect.

The evident paucity of research on the specific effects of carers PBs following the introduction of the Care Act leaves an obvious gap for this thesis to fill. Talking with carers about their experiences of PBs under the Care Act (2014) opened up the possibility of hearing first-hand accounts of whether the Care Act (2014) duty to meet the eligible needs of carers and intended effect of promoting carer wellbeing through PBs was having any materially positive effect.

In the next chapter readers are introduced to the methodological approach used to design and implement the qualitative primary enquiry, to explore insights from carers themselves about the impact that PBs were having on their lives. This is accompanied by a rationale and justification for this qualitative phase in research philosophical terms.

7.4 Methodological approach to qualitative data collection

7.4.1 Recruitment and participant sample

A convenience sampling strategy was adopted for the qualitative enquiry element of phase three. Participants were recruited from a local charity that supports the needs of people with caring responsibilities. The charity offers a range of services including advice and information, advocacy, and group support. It also carries out development work in its locality working with local statutory and voluntary providers, to raise awareness of the needs of carers, such as the importance of carer recognition in primary and secondary care settings. This organisation was chosen because it serves a diverse range of carers and I am a member of the charity’s board of directors in the role of volunteer trustee, from 2013 to present. Although I am known to other board members, I had no pre-existing relationship with any carers who accessed the service for advice and support. Therefore, there was no concern that carers would feel obliged to take part in the study, or concern that their decision not to take part would in any way affect the level of support they received. This was made clear in the participant information and consent paperwork.

A further primary reason for choosing this organisation was its wide geographical coverage in the region my study is based, and the demography of areas covered included wards that score highly on the government's index of multiple deprivation (IMD) (The Office for National Statistics, 2015). The IMD measures relative deprivation in (neighbourhoods) of England, referred to as lower-layer super output areas. Seven domains comprise the index which are: income; employment; education, skills, and training; health and disability; crime; barriers to housing and the built environment. My aim was to recruit carers from across the socio-economic spectrum. One of the ways I would be able to determine this was by finding out if the person being cared for had to contribute towards the cost of their social care. People who have the full cost of their care funded by the LA have income and savings below £14,250 annually and those who are self-funding (pay for the full cost of their care) have income and assets above £23,250 per annum (only the income of the person being looked after can be considered in this calculation). Although this not an absolute measure of means, because the carer could have their own income source, it does establish variation in the sample based upon income.

I met with the Chief Executive and carers' services manager to discuss my aims and objectives and we discussed the most appropriate way in which they could support me to access a wide range of participants.

A poster advertising my research aims along with a participant information sheet were emailed out to more than 250 carers on the organisation's database. Carers were invited to contact me either by email or telephone if they were interested in finding out more or taking part. A total of 30 potential participants expressed an interest, and all were contacted and asked to take part in a screening questionnaire to assess their suitability for the study. The Care Act (2014) only applies to adult carers, caring for adults and so the study excluded carers under the age of 18 or those caring for a someone under the age of 18. Although this was made explicit on the advertising poster, four participants were excluded on this basis. Other participants (six) were excluded because they confused carers allowance with a carer's PB. The former is paid by the Department for Works and Pensions and is given only to carers under the age of 65 who are caring for 35 hours or more per week because it is viewed as an income replacement benefit. These two factors reduced the sample size from 30 to 20 participants.

A total of 17 interviews were carried out as three participants withdrew prior to interviews commencing.

7.4.2 Strengths and limitations of methodological approach

The convenience sampling strategy had several benefits. As well as the wide socio-demographic characteristics the carers' charity serves; it allowed me to reach a cross section of carers (see table 14 below). Qualitative methods of data collection and analysis do not allow for the generalisation of findings beyond the sample. However, that is not the intention of qualitative research (Ritchie *et al.*, 2014). The purpose of the qualitative phase was to explore depth of meaning rather than gain breadth of carers' responses to this element of the enquiry.

Convenience sampling is a tried and tested sampling strategy frequently used in qualitative research (Given, 2008). The sample obtained was non-representative of the carer population.

However, by sending out the poster to all carers on the organisation’s database, this gave me the greatest chance of sampling a heterogenous sample of carers as possible. Heterogeneity in sampling is aligned with rigour and reliability within qualitative methodologies (Ritchie *et al.*, 2014). It means the sample has greater diversity, and therefore a richer set of data will be captured consequently. Having said that you can see from table 14 below that most carers taking part were female and the mean age of respondent was 63. The mean age of caring according to Census data (2011) is 55 so my sample represented a slightly older demographic of carer compared to the England average.

One of the limitations of my sampling strategy was using a carer specific organisation. This meant all study participants understood and identified with the term carer and applied it to their own circumstances. It has been established in the genealogy of caring that people do not always identify with the label of carer, and this can be one of the barriers in accessing support. If the term holds little or no meaning, you may be less likely to approach or accept the help of a carers’ centre model of support. Therefore, the study does not elicit the views of people with caring responsibilities who may be receiving a PB, but do not identify with the term carer to describe their activities. This is a limitation of the study because those people with caring responsibilities may voice a different account about the impact of PBs compared with those who do identify with the term. This limiting factor, therefore, increased the risk of bias in my sample because participants may have shared too many characteristics in common.

Carers were offered a £15 gift token in recognition of the time given to participate in an interview and was offered in the spirit of gratitude for their participation. Careful thought was given to the coercive element that incentives play (Bryman, 2016). However, I made a judgement that the figure arrived at was not sufficiently high enough to coerce people to take part, but equally may encourage carers to come forward who may not otherwise.

7.4.3 Sample characteristics

Table 14 below shows the socio-demographic characteristics of the participant sample. There were 17 participants, 14 women and three men. The column headed: *Length of caring role* is presented in descending order and except for Vicky, participants caring for the longest time period are parent carers. The mean length of a caring role is 13 years. The *Person cared for* column, refers to the relationship and condition of the person being looked after. The *Duration of direct payment* column illustrates how long each participant has been in receipt of a carers DP for. All sample participants were offered a carer's PB in the form of a DP, if they met the eligibility criteria following assessment. No one in the sample was offered an alternative mode of PB administration, such as part DP or managed PB. Lastly, *funding status of cared for* denotes whether or the not the cared for contributes financially towards the cost of their care.

Service users with income and savings above £23,250 who pay the full cost of their care and are referred to as *self-funding* in the column titled *funding status of cared for.* Between £14,250 and £23,249 the LA will pay for some care costs and the service user will contribute the remainder according to a sliding scale; these are referred to as *partial funding* in the table. Income and savings below £14,250 means that the LA will pay the full cost of care, these are denoted as *full funding* in table 13. The purpose of including these data is that they give a non-exact indication of household income (it considers assets of the service user only).

Having an approximate indicator of household income could act as a proxy measure of how much income influences the extent to which participants felt able to exercise choice and control over their own lives and the extent to which their PB promoted their wellbeing.

Parent carers made up three out of the four study participants who supported someone whose care was paid for entirely by the state. Two out of three participants cared for a spouse who contributed towards the cost of their care and three spousal carers looked after a partner who paid the full of their care. Of the remaining seven, three cared for a partner who had been found ineligible for support following a service user assessment, and four whose partner had not had any contact with adult social care, and therefore had not had a service user assessment of need.

7.4.4 Descriptive findings

In table 14 below, 78% (N=14) of participants interviewed were female, and 22% (N=3) male. The mean age of sample participants was 63. The majority (65%) of the sample participants were spousal carers, co-resident with the person they cared for. Adult children caring for ageing parents made up 18% of the sample, where two participants (Denise and Victoria) lived with their mothers who they looked after. Pauline, Kate, Dot, and Gillian were parent carers and represented 24% of the sample population. Parent carers were co-resident with their adult children, with the exception of Kate whose son was accommodated by the LA shortly before the research interview. She and her husband were unable to carry on caring for their son at home. Parent carers in the sample were more likely to be living in households with lower incomes compared to spousal carers in the sample, with three out of four parent participants caring for an adult son or daughter who had the full costs of their care met by the LA. These parent carers in the sample were caring full time and not able to combine caring with paid employment.

The nature of the caring roles varied across a range of physical, mental, and learning difficulties and disabilities. Carers in the sample had been in receipts of a DP for between one month and three years.

Table 14. Participant sample (all names changed to protect confidentiality)

Participant	Age	Length of caring role	Person cared for	Duration of carers direct payment	Funding status of cared for
Pauline	68	50 years	Daughter with complex physical needs	1 month	Full funding
Vicky	75	43 years	Husband following brain injury	1 year	Self-funding
Kate	44	21 years	Son with complex physical and learning disabilities	3 years	Full funding
Dot	52	21 years	Son with severe autism	1.5 years	Partial funding
Gillian	55	18 years	Son with complex physical and learning disabilities	No outcome	Full funding
Bob	77	7 years	Wife with Alzheimer’s	2 years	Self-funding
Dave	60	7 years	Wife with Parkinson’s and Lewey body dementia	10 months	Partial funding
Belinda	66	6 years	Husband with Alzheimer’s	2 years	Self-funding
Jack	63	6 years	Wife with LTC and breast cancer	No outcome	No assessment
Denise	32	5 years	Mother with Parkinson’s disease	6 months	Partial funding
Michael	75	5 years	Wife with Alzheimer’s	2 years	Full funding
Mary	67	5 years	Husband, chronic illness LTC	Not eligible	Not eligible
Dianne	65	4 years	Husband with Parkinson’s disease	1 year	Not eligible
Rachael	66	4 years	Husband with dementia	No outcome	No assessment
Victoria	77	3 years	Mother, elderly/frail	2 years	No assessment
Jane	64	3years	Husband with chronic illness	1.5 years	Not eligible
Caroline	65	3 years	Mother with Alzheimer’s	Assessment denied	No assessment

The next section addresses the approach to qualitative data analysis, and why thematic analysis was chosen as a method to analyse interview data.

7.5 Methodological approach to qualitative analysis

One of the key reasons for using Braun and Clarke's approach was its widespread use in studies that draw from multiple theoretical frameworks (Braun and Clarke, 2006). Their six phased approach to thematic analysis is cited as one of the most widely used in qualitative research (Bryman, 2016) and is considered *"a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of the data"* (Braun and Clarke, 2006, p. 78).

Having said that, a significant critique of thematic analysis is offered by Bazeley (2013) who argues that researchers using the approach, often do not specify sufficiently how they are using it, and/or the process by which themes are extracted from the data. Other criticisms have pointed to a lack of justification as to why themes identified are considered most influential or meaningful and other data are not (Braun and Clarke, 2006; Bryman, 2016).

It is in response to this critique that Braun and Clarke developed their six stepped approach. Offering researchers, a systematic way in which to introduce rigour and reliability to the analytical process. The authors are careful to stress that researchers do not have to follow each step slavishly but rather to adapt and/or merge the six stepped approach to fit their own study's design. The six steps are set out below, with a description of how I applied their approach to the creation of themes. This shows readers the analytical and cognitive process that took me from transcript to theme.

7.5.1 Phase one: Become familiar with the data

In phase one I made initial notes from the first read through of transcripts, jotting down early impressions, and highlighted sections of text about interviewees experiences of the care and support planning process (encompassing how carers accessed help and support, assessment and PB planning processes and PB impact). During the second read through of transcripts, I began to compare these initial notes and highlighted sections to identify patterns of similarity and difference both within and across participants' accounts. Early impressions, and highlighted sections identified commonality around the care and support planning process. This encompassed ways in which people accessed adult social care; how they obtained and experienced the carer's assessment and eligibility processes; the ways in which they received support (either as PB or some other outcome) and the difference (if any) that PBs were making to their lives. These early impressions of the data reflected the way in which interview question themes were structured around their experience of the care and support planning process in its entirety.

Phase one, according to Braun and Clarke (2006), involves reading and re-reading transcripts, because this is considered an effective way of becoming familiar with your data set. It is this stage of *"active reading"* (p.87) that supports the researcher's ability to begin to find meaning, patterns, and themes within the text. Braun and Clarke distinguish between a deductive, theoretical analysis where the research question(s) drive the analytical process and an inductive, bottom up, data driven approach where the raw data lead the way. This study adopted a hybrid mix of both deducted and inductive approaches where the question informing phase three of the study *'what difference do PBs make to carers lives?'*, and the raw data both played an important part in the process toward identifying overarching themes based upon patterns of similarity and divergence in the data.

Although this section is presented as a liner, step-by-step guide, the process itself became an interactive and reflective one where codes and initial themes were revised along the way, to ensure that developing themes were grounded in the original data. The primary objective was to represent the subjective viewpoint of carers, about the difference that PBs were making to their lives and explore their experience of the care and support planning process, that captured how PBs were administered.

7.5.2 Phase two: Develop codes from the material

This is considered the initial coding phase, where the focus is on organising the data into meaningful groups (Braun and Clarke, 2006). I began to organize the early impressions, and highlighted sections from phase one into smaller chunks of meaning, by arranging the data in two stages. In stage one I created a matrix (by hand), with statements/initial codes across the top of the table that corresponded with patterns of similarity in what interviewees said. This was structured according to data extracts that either addressed the research question specifically or captured an element of the care and support planning process that was important and interesting in understanding participants' experiences, because they voiced something that impacted upon their ability to have a life of their own alongside caring and/or affected their wellbeing. For example, patterns of similarity about interviewees' experiences of the carer's assessment and support planning process came up repeatedly and was discussed by 13 out of the 17 interviewees. These extracts were initially coded as *Assessment & support planning process is problematic & overly complex*.

A number of other codes were created, that spoke to a pattern in the data that reflected specific obstacles and challenges, for example, in relation to the PB allocation process; difficulties in making first contact with adult social care and the emotional challenges of caring that impacted your ability to live your own life. Table 15 below shows an example of the matrix with data extracts as supporting evidence of each code. Thirty-five preliminary codes were created during phase two of the analysis.

One of the things I found during this stage, was that several of the data extracts could be coded more than once because they spoke to more than one theme. For instance, under the codes *fight/battle for help/support* (see table 15 column one, row two), a number of extracts included accounts of specific challenges with, for example, the assessment and/or DP process or contacting the LA. I had to make an analytical decision about where to place these extracts and did change my mind more than once as the matrix generated new codes. These new codes sometimes became a more accurate reflection of extracts, and it was often on this basis that I recoded extracts. For example, some of the extracts that were originally coded under *Assessment and support planning processes are problematic and complex,* were recoded under *No choice over how DP is spent, because* the extract spoke specifically to ways in which the DP could only be spent on paying for replacement care. In some instances, I did code data extracts under two codes. For example, *"I think they assume you'll automatically do it [...] it would be nice to have more family involved, but they're all working."* were coded under *caring is primarily seen as the responsibility of the family* **and** *expectations that extended family can and should help* because of the references to both caring being seen as the responsibility of the family, **and** the desire for more family help. The reasoning for double coding was to preserve the integrity of the text and reduce the effect of 'cutting' data extracts and losing meaning from the extract by creating an artificially imposed cut by the researcher.

Creating a matrix served several purposes. Firstly, it showed how much evidence (in the form of data extract) there was for a particular code of meaning/importance. Secondly, it offered up the opportunity to examine variation, within and between respondents. In other words, identifying any discernible patterns within a respondent's account, across the codes, but also any patterns of similarity and difference between respondents.

Transcripts were also inputted into NVivo qualitative software to aid the thematic analytical process.

7.5.3 Phase three: From codes to themes

At this stage I began to review the 35 codes generated in the matrix and noticed a pattern where many of the codes could be grouped together, because they shared a similar topic and/or captured something important about the research question and interviewees' experiences of factors that shape and influenced their ability to exercise choice and control over their own lives and difference that PBs were making.

I used colours to group codes together, where they shared a pattern of similarity as can be seen in table 15 below. Yellow was used to group together codes that spoke to the practices and processes that made up the carer's assessment and PB planning processes; that voiced the challenges and barriers that interviewees experienced. Red grouped together codes that expressed the importance and influence of relationships in supporting interviewees' participation and inclusion in economic and social life. Whether that was being able to have just a few hours of respite per week or being able to access broader life opportunities, such as employment and relationships. Blue highlighted codes that spoke to the impact of emotions and feelings, that shaped the extent to which interviewees felt they had choice or control and were able to take a break or think of their own needs, with or without a PB. Green grouped codes that spoke to the 'responsibilising' effect of caring and the impact of feeling responsible for the provision of care, in shaping the extent to which interviewees felt they had choice, in being able to think and plan their time away from caring.

In searching for themes, Bryman (2016) suggests that it is helpful at this stage to write summaries, detailing how the themes came into being.

At the end of this step in the thematic process, I was left with codes that were organized into preliminary themes that appeared to say something important about the difference (or not) that PBs made to carers' wellbeing, and factors that influenced the extent to which interviewees felt they could exercise choice and control, in the way in which they thought about, and were able have a life of their own/participate in social and economic life.

Preliminary themes expressed a range of factors, that shaped the degree to which PBs enabled participants to use their budget, in a way that promoted their wellbeing, participation, and inclusion. Assessment and support planning practices; relationships with the cared for, professionals and LA; the effect of emotions on choice and control and responsibility of care were key, both to accessing assessment, support and PB, and for the PB to have any materially positive impact on participants' lives.

Some codes remained, however, that did not fit neatly into one of the colour coded themes. These were: 1) *Unsupportive employers make it hard to maintain work with caring*, and 2) *Lifetime caring gets harder as you age*. There was very little evidence in the way of data extracts to support these codes, for example, only one interviewee referred to their need to give up work to care and cited their employers lack of support and flexibility as the reason. Two out of the four lifetime (parent carers) voiced how getting older was taking a toll on their health and wellbeing. Because of the limited nature of the supporting evidence for these codes, they were not included in the formation of themes, however, are included in the wider discussion chapter.

Table 15. Preliminary themes and corresponding codes grouped by colour

Preliminary theme one - Yellow codes –Assessment and support planning practices and processes	**Preliminary theme two** - Red codes – Importance of relationships to carer wellbeing and inclusion	**Preliminary theme three -** Blue codes – Effect of emotions on participation and inclusion	**Preliminary theme** four **-** Green codes – Responsibilising effect of caring on wellbeing
Fight/battle for help/support	Nature and quality of paid care impacts carers wellbeing and participation	Guilt at thinking/wanting to meet you own needs	Caring seen primarily as the responsibility of the family
Assessment and support planning processes lack clarity and transparency	If you cannot leave the cared for person then your choices are limited	Caring can make you feel guilty and resentful at the same time	Expectation that extended family can and should provide help
No choice over how DP spent	Opportunities to have/maintain relationships are limited	Frustration at lack of recognition from cared for, professionals and Government	Caring is seen as women's work
Carers DP makes little/no difference	Challenging to meet you own needs if cared for will not accept outside help	Feelings of lack of control and autonomy over caring	No choice over whether to care
If you turn down a DP as sitting service, nothing else offered	DPs in the form of siting services have limited effect	Gratitude at receiving DP mixed with frustration at limited scope	
Help only comes at crisis point	Hard to attend to your own needs		
Difficult to remember the assessment process			
Carers DPs need more flexibility			
Carer's knowledge not valued by professionals.			
System designed to stop you getting help			
You find things out for yourself			

7.5.4 Phase four: Review and evaluate themes

The fourth phase operated on two levels. Firstly, I reviewed the matrix, to examine if extracts really fitted newly created themes. It was at this stage, that some data extracts were recoded where they appeared a better fit elsewhere. For example, I had coded some extracts under *carers DP need more flexibility,* where interviewees spoke about the limited and restrictive nature over how they could spend their DP. I realised that this could be coded under the yellow theme of *practices and processes of care and support planning,* because decisions about what the DP could be spend on was part of the support planning conversation.

Secondly, I reviewed the preliminary themes shown in table 15 above, and re-read the data extracts associated with each theme, to consider whether the data really did support it. I felt confident that the data extracts supported the preliminary themes, in terms of themes working both with a single interview transcript, and across all transcripts. It was also important to think about whether the themes worked in the context of the entire data set.

7.5.5 Phase six: Report production

In the final stage, *"fully worked-out themes"* are produced to explain the findings of the study (Braun and Clarke, 2006, p. 93). The findings from the thematic analysis of interview data are set out in the next chapter where sub-themes act as sub-headings, and data extracts from interviews are used as supporting evidence of each of the two themes created. This approach provided a visible trail, from findings to thematic map, showing how data extracts corroborate the coding scheme and development of sub-themes through to theme (Bryman, 2016).

7.6 Trustworthiness

A common criticism of qualitative research is that it lacks methodological rigour; although it is widely agreed that this position stems from positivist epistemologies, with their central concern being the lack of generalisability from qualitative studies (Koch and Harrington, 1998; Mills, 2017). However, qualitative research does not aim to be generalisable, although illustrating representativeness is an important part of qualitative research practice (Denzin and Lincoln, 2011; Ritchie *et al.*, 2014). Introducing the quantitative elements to my design increases the reliability of my study, because the views expressed by carers, from the semi-structured interviews, enabled me to compare them against the picture presented by the national data sets.

Context bias is another important consideration in the trustworthiness of qualitatively focussed research. In particular the risk of social desirability, that interview data poses. This refers to respondents giving answers to questions they think researchers want to hear (Groves, 2009). I reflected on this in relation to my own position in the social hierarchy, and background as a social worker and how that may influence respondents. This is considered below in the section on ethical considerations.

Other critiques of qualitative methods, round on their failure to effectively operationalise models and theories (Mills, 2017). Again, this position stems from positivist philosophical underpinnings about the nature of reality being observable and measurable in an objective way. However, as the previous discussion has shown, the concept of scientific absolute truth is of itself a contested one, and this thesis takes the position of pragmatism, and the notion of an objective, neutral fact, is of itself a socially constructed one (Burr, 1995).

Validity is described as, *“a process whereby the researcher earns the confidence of the reader that he or she has gotten it right”* (Hesse-Biber and Leavy, 2006, p. 48). The concept of trustworthiness replaces the positivist epistemological concerns to establish absolute truths (Hesse-Biber and Leavy, 2006). By ensuring that the inquiry demonstrates validity, the researcher is aiming for findings to be considered a sound, and trustworthy explanation of the area of study, that their inquiry should be considered and attention paid to it (Hesse-Biber and Leavy, 2006; Lincoln and Guba, 1985) According to Kvale (2015), there are three criteria determining validity in qualitative research. The first is validity being established from a perception of the researcher’s moral integrity and credibility, and demonstrated in the quality of research that they have carried out (Kvale, 2015). I have sought to demonstrate my integrity and credibility through my transparent account of the research task, and data analysis. The second criterion is communication, in the researcher ensuring that interpretations and findings are available to the wider community for discussing, and refutation (Kvale, 2015). The final criteria are the pragmatic application of knowledge in practice, developing the idea that one needs to go further than just communicate justification of the knowledge that is claimed via the research. *“Pragmatic validation rests on observations and interpretations, with a commitment to act on the interpretations”*. They view this pragmatic approach to validity as offsetting the potential of the social constructionism epistemology to *“circle around in endless interpretations”* (Kvale, 2015, p. 292).

Reliability is established by seeking internal and external consistency, alongside the criticality of the researcher (Hesse-Biber and Leavy, 2006). Internal consistency is found in the researcher questioning that data collated is reasonable, fits together, and has some consistency over time (Hesse-Biber and Leavy, 2006). Additionally, checking the generated data against other research findings, enables consideration of external consistency (Hesse-Biber and Leavy, 2006). The findings of the qualitative inquiry are mixed with findings from the narrative synthesis in the discussion chapter; considering where they converge or diverge from other research in the field. However, essential in establishing reliability is the researcher's application of criticality of the data generated, including insight, awareness, suspicions, and questions (Hesse-Biber and Leavy, 2006).

Whilst the process of analysing qualitative data does not need to imitate the procedures upheld by positivist epistemologies, it is also evident that the analyst needs to engage thoroughly with the data. This was achieved by adopting the phased approach of Braun and Clarke (2006), along with the application of Bacchi (1999) WPR mode of policy analysis.

7.7 Ethical considerations

The overriding priority remains my responsibility to protect the safety, and wellbeing of participants who gave their time and knowledge to take part in this study.

There is an extensive literature on the burdensome nature of caring, both physical and emotional (Barnes, 2006; Carers UK, 2018; Carmichael and Ercolani, 2016; Garlo *et al.*, 2010; Larkin and 2011; Larkin, 2015; Twigg and Atkin, 1994; Yeandle and Buckner, 2017). Carers can often report poorer health and wellbeing outcomes compared to the non-caring population, which may indicate a vulnerability. Interviewing carers, to gain their insights about the difference that PBs make to their lives is imperative if we are to develop meaningful social work practice, based upon principles of human rights and equalities. The Care Act recognises, for example, that caring should not prevent you from entering or maintaining employment, with personal budgets a key driver in supporting that process. This research will shine an important spotlight on the effectiveness of a legal framework in protecting carers from the stresses and strains and promote their wellbeing and inclusion in economic and social life. Speaking to people with first-hand experience of caring was therefore imperative in order to gain subjective experiences of caring impacts, in order to corroborate and/or challenge the findings from the first two phases of the study.

Active steps were taken to support participants during the study period. Participants were offered a de-brief at the end of the interview to discuss any issues that may have arisen. A list of local carers support groups was offered in case of any ongoing support needs. As a trained social worker, I am experienced in communicating with people in distress. The limits of confidentiality were discussed with all participants, in relation to the protection of vulnerable adults.

Ethical approval for this research was obtained from the University of Essex ethics and research committee on the 3rd of May 2018. An amendment to the ethical approval was granted by the University of Essex on the 26th of November 2018 which agreed to the transcription of 12 out of the 17 interviews by an external, secure transcription service. I am also guided by the social work regulator's code of professional conduct (Social Work England). Research raises several ethical questions and dilemmas which are set out below:

Power – Taking on a role, whether that be social worker or researcher by the very title suggests a position of power. It is important for the researcher to be aware of the power vested in their role and the effect this may have on participants. For example, it is possible that some participants may feel obliged or compelled to take part. Ensuring consent is gained in a sensitive and open manner was a task I took seriously. Participants should not feel any coercion to take part, which is why my incentive of £15 gift voucher felt sufficient as a mark of gratitude for giving up their time whilst not being high enough to coerce involvement. Having my own personal experience of caring and professional career working in the field of carers' policy and practice meant I felt the research was less open to exploitation in terms of advancing my own career at the expense of using the stories of carers, to develop my own theories about the benefits and differences personal budgets make. Beresford and Croft (2001) refer to the importance of researchers needing to ensure that they are not exploiting the experiences of others for their own professional advancement.

Where it felt appropriate, I shared some of my own experience of caring (this happened in approx. 50% of interviews). Where this occurred, it seemed to help the carer open up more about their own experience, as I may have been viewed as someone who could empathise from a personal perspective. In those cases, I think it helped to develop a sense of trust between myself and the individual.

Being open and transparent about the aims of my research helped to alleviate concerns and questions as each participant was sent a copy of the information sheet outlining the purpose and aims of my research. People were invited to contact me by telephone or email to discuss their participation. It was at this stage I could assess their suitability by taking them through a screening questionnaire to ensure they met the study criteria. I only wanted to interview adults looking after adults who had had a carers assessment and or a PB following a carer’s assessment. The initial telephone call also presented an opportunity to answer any questions participants may have had about taking part and what it involved. This initial telephone call also acted as an ice breaker, and scene setter for the face-to-face interview.

It is also important for researchers to consider issues of anonymity and privacy. It is important to ensure consent is informed and each participant was taken through a detailed consent form which we both signed. This outlined how data was collected, stored, disposed of, and used to produce the research. Participants were giving pseudonyms and any identifying information (names, places) was kept confidential. Limits to confidentiality were also laid out. This was discussed in the context of a vulnerable adult being put at risk of harm or abuse based upon something a participant may say. I explained that this would need to be discussed and the relevant authorities informed if I thought a vulnerable adult may not be able to protect or keep themselves safe.

Findings from the analysis of semi-structured qualitative interviews are presented in the next section.

7.8 Results

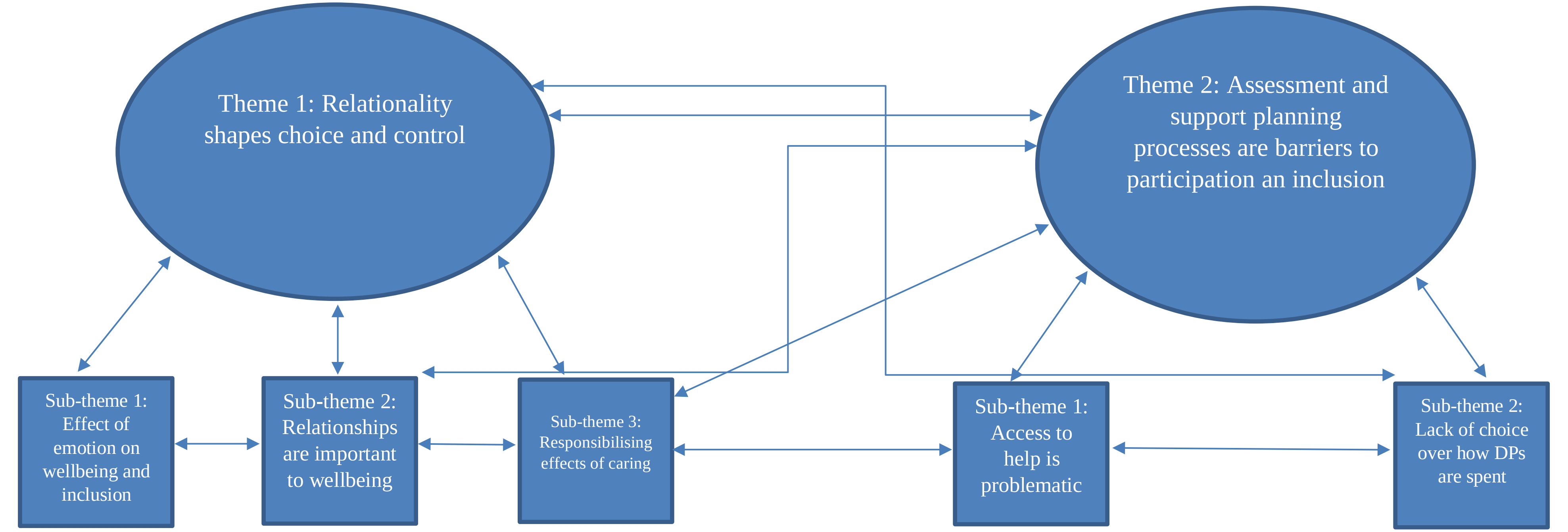
This section presents findings from 17 qualitative semi-structured interviews, held with participants with caring responsibilities (carers), who agreed to be interviewed about their experiences of receiving personal budgets (PBs), from a Local Authority (LA) in the East of England. A key qualitative objective of this phase was to understand from carers themselves the impact that PBs were having on their ability to have a life of their own alongside caring. This corresponds with the study's overall aim to assess the claim that the Care Act (2014) can fulfil its duty to promote the wellbeing of carers using PBs. Interviews were held between June and December 2018.

Two themes were created from the data. The first theme was called: *Relationality shapes choice and control* and the second: *Assessment and support planning processes are barriers to participation and inclusion*. Each theme is presented on a thematic map shown in figure nine below, with their corresponding sub-themes and codes. Two-way arrowed lines indicate the interaction between sub-themes, and themes and illustrate how the interactions are multi-directional.

Both themes speak to the way in which individual and organisational practices shape the way in which participants in the study experienced the carer's assessment and support planning process. The transactional mode of delivery of PBs in the region where the study was conducted had a significant influence on a participant's ability to participate in economic and social life. The one off, one size fits all PB mode of delivery took no account of the relational nature of the caring role, and how the interdependency that existed between the carer and the person they looked after fundamentally affected the wellbeing of carers and the extent to which participants felt able to have a life of their own and exercise choice and control.

Data extracts were used as supporting evidence of a theme and were grouped together by sub-theme. The thematic map on the next page shows the relationship between themes, sub theme and their corresponding codes.

Figure 10 Thematic map showing themes, sub-themes, and corresponding codes



Codes for sub-themes one to three of Theme 1:

- Nature and quality of paid care impacts wellbeing
- Opportunities to have/maintain relationships are limited
- Guilt at thinking about your own needs
- Caring can make you feel guilty and resentful at the same time
- Frustration at lack of recognition from the cared-for/professionals and government
  Feelings of lack of control and autonomy over caring
- Caring seen primarily as the responsibility of the family
  Gratitude at receiving DP mixed with frustration at limited scope
- Expectation that extended family can and should provide help
- Caring is seen as women's work
- No choice over whether to care

Codes for sub-themes one and two of Theme 2:

Fight/battle for help/support
Carers' knowledge not valued
Assessment and support planning processes lack clarity and transparency
Help only comes at crisis point
Difficult to remember the assessment process
No choice over how to spend a DP
Carers DP makes little/no difference
Carers DPs need more flexibility
If you cannot leave the cared for then choices are limited
Challenging to meet you own needs if the cared for will not accept outside help

7.9 Overview of themes

Two themes were created using thematic analysis, these were:

1. Relationality shapes choice and control
2. Assessment and support planning processes are barriers to participation and inclusion

The thematic map above uses arrows to indicate the relationship between sub-themes and themes. Two-way arrows show how sub-themes and themes provide a context for each other. For example, the inter-dependency between themes is characterised by the way in which assessment and support planning processes are shaped by the nature of relationships between carers, the person they care for and professionals and formal services entering their lives. Assessment and support practices rarely took account of the importance and effect of the caring relationship, in determining carers' eligibility for support. Nor did assessment and support practices acknowledge the limited effect of a 'one size fits all' mode of delivery to PBs, in the form of replacement care. The transactional model of delivery experienced by all study participants was blind to the relational nature of the caring role. If the person being cared for did not want to accept outside help, then a carer's DP, in the form of replacement care, was ineffective. If the carer did not want to leave the person they cared for but preferred to spend their DP in a way that meant they could enjoy an activity or experience as a couple this was not permitted. Choice on how a DP could be spent was extended to two out of the 17 participants who took part in the study. Choice and control are two fundamentally important principles on which the Care Act (2014) was founded, yet findings from the thematic analysis of interview data suggest that choice and control are complex concepts to give meaning to, and to apply in the context of a caring relationship.

In the next section, findings are presented in relation to each theme, and sub-themes are used as sub-headings, to describe both the detail of each theme, and to illustrate the connections between them. Extracts from interview data are used as corroborating evidence of analytical statements made in support of each theme.

7.9.1 Theme one: Relationality shapes choice and control

This theme speaks to the emotional aspects of participants being able to express a desire to have a life of their own. The degree to which participants were able to exercise choice and control over how they lived their own lives was mediated by the relationship they had with the person they looked after. Participants' needs were often inextricably linked with those of the cared for. Such that positive wellbeing for the carer was dependent upon the wellbeing of the cared for.

7.9.1.1 Sub-theme one: Effect of emotion on wellbeing and inclusion

The emotional or relational aspects of care, brought about a mix of feelings, including, love, duty, guilt, and resentment for participants. These feelings were tied in with a sense of responsibility towards their caring roles. Four participants positioned accounts of their role in the context of marriage vows, and a sense of duty and obligation that came from that contractual obligation.

The concept of relationship was central to all participants' experiences of caring. The type of relationship between study participants, and the person they cared for appeared to influence decisions about the type of care and support participants received, and the extent to which participants felt able to take a break from their caring role.

Analysis of interview data showed that complex feelings were aroused by the nature of the relationship, and these feelings could act as a barrier to participation and inclusion, particularly if the carer felt guilt for wanting to pursue their own interests.

For example, consider Victoria. She lived with and has cared for her elderly frail mum of 94 for three years. She had been in receipt of a carers DP for two years at the time of the interview.:

Extract one: *"I don't do it because I want to, I do it because it's my duty […] I gave up my life in Spain to come back to look after her […]. We don't have a great relationship. We didn't really get along when I was growing up […] she's very demanding […] I get very little time to myself; she constantly wonders where I am and will shout after me if I go upstairs [...] it's very wearing".*

Jane looked after her husband with dementia. In this extract she highlighted the difficulty of balancing her desire for a break alongside the cost of paying for both a holiday and care. and the guilt which accompanied her thoughts:

Extract two: *"I would love to have a holiday [...] I couldn't put him in a nursing home, because it just wouldn't be any good for him mentally, and it's not fair anyway. I would feel bad".*

Jackie looked after her husband with a long-term condition (LTC). She had received a carer's DP which she used to pay for someone to sit with her husband while she did the shopping. She felt guilt leaving him with strangers.

Extract three: *"You feel guilty. Very guilty. I feel guilty at times when I come out and leave him with the carer, even just to do a bit of shopping."*

Dave is 60 and has cared for his wife with Parkinson's and Lewey Body dementia for the last seven years. Here he talked about his caring role in the context of his marriage vows and the sense of self-sacrifice this involved, which at times can also brought about feelings of frustration at the lack of recognition from his wife:

Extract four: *"She's my wife, she's my responsibility. I'm married to her, I value my marriage vows, end of. That's it. In sickness and in health […] I really don't care about me at all. All my time goes into my wife […] probably five times out of ten, I get no recognition for that from her and that gets extremely frustrating."*

Later in the interview Dave described how his sense of responsibility made it difficult to ask for help:

Extract five: *"You think you can cope. Then after a few years, you're thinking – I mean, it took me probably about 14 years to ask for help. Primarily because it's my responsibility. I'm gonna [sic] do this. I don't need anybody else."*

Jack, 63 cared for his wife with an LTC and breast cancer. Here he referred to a reciprocity in his relationship. Knowing that his wife would care for him if roles were reversed:

Extract six: *"I'm of the old school where when you marry somebody, it's sickness and in health and what have you. I know* [wife's name] *would do exactly the same for me."*

In the following extract, Mary (who cared for her husband with a chronic illness) reflected on caring for her mother when she was younger and the challenge of caring with competing demands of family and work, and the conflicting emotions of love and guilt that can emerge:

Extract seven: *"I would look after my family to the end of my days. My mum, I know I was really worn out, after when she died, but I would have carried on. I felt ashamed of my feelings, but I was relieved when she died. I was so tired. I was full time, I had a family, trying to live our life."*

Later, in the interview she talked about how decisions about longer term care for her husband were framed around her ability to cope with caring. Implying that she would only consider residential care as an absolute necessity; when she was physically no longer able to carry on providing care:

Extract eight: *"I wouldn't choose not to do it. This is what I signed up for. I have no resentment […] .if you put it the other way around, I wouldn't be cared for as well. People tell him he's lucky, and he's alive today because of the way I care for him. But no, no resentment, and I wouldn't change it. I couldn't put him in a home. I will make the right decision at the right time. I'm not far off cracking […] .I sometimes feel like inside my head I'm screaming, 'what about me?'"*

Two participants referred to the effects of time, on their ability to care, and enjoy their own lives. This implied that care can also be a temporal experience where time and longevity of caring appeared a significant factor in shaping participation and inclusion. This was particularly the case for Pauline, Dot, Gillian, and Kate who were lifetime carers, looking after their now adult children. They had a combined 110 years of caring between them.

Pauline had cared for her disabled daughter for 51 years. In the following extract she highlighted how the ageing process was beginning to take its toll:

Extract nine: *"I think when you're younger you just cope with it but as you get older you just you get tired. It's just normal isn't it? You should be retired and doing retired things and* *enjoying yourself and really you know, it erm, [sic] it's a struggle. I don't have much time for myself and I find I get tired very easily now."*

Codes that comprised the preceding nine data extracts, highlighted data that spoke to the effect of emotions on a carer's ability to have a life of their own, and the inextricable link between the needs of participants, and the person they cared for. If care and support met the needs of the person, they looked after then often this had a positive impact upon participants' wellbeing.

What these extracts imply is that decisions and choices are not solely based on what is best for the carer's wellbeing. It is also very much framed in terms of what is right for the cared for too. In Mary's case (extract eight), her ability to choose what she wanted for herself was influenced by her ability to carry on caring. She hinted that if the 'boot were on the other foot', perhaps she would not receive the same level of care from her husband.

7.9.1.2 Sub-theme two: Relationships are important to wellbeing

Finding paid carers, you can trust can be challenging, and the relationship between paid care staff and family carers was critical to participants feeling able and confident to leave the person they looked after knowing they were in safe hands and being well cared for. Bob, who had looked after his wife with Alzheimer's disease for seven years, and had received a carer's DP for between two to three years, was frank in his response:

Extract 10*: "Quite honestly, half of them* [paid carers] *were useless. One or two were very good and helpful, but the youngsters – or a youngster, probably about 20-25, very smart uniform, but every time I came back, they had the telly on and were sat watching telly, so not doing nothing [sic] [...].Basically, it boiled down to you had somebody in the house, so you could go out for a couple of hours and know that she was safe."*

Bob referred in his extract to the limited role of replacement carers, as a service to keep the cared for person safe, and nothing more. Jane highlighted another limiting role of sitting services, where there was a discrepancy over the price the LA paid to agencies who provided replacement care, versus the price agencies charged to carers and service users on the private market. In this extract she described how the hourly rate the LA paid for her carers DP, did not cover the hourly rate the agency she contracted with to provide replacement carers. The effect being that she received fewer hours than her DP suggested because she paid a higher rate to the agency than the LA was willing to:

Extract 11*: "No, I said that to her. I said, 'What you're paying,' at the end of it when I reapplied, because you have to reapply again* [for a DP], *I said, 'There's no way you can get somebody to come in for £13 to sit'[…] I think she's now upped it to four hours a week. If she paid me four hours a week, I would be able to get three hours care, because the care is more expensive than they're* [LA] *willing to pay".*

What may have happened in Jane's case was that the LA was applying the hourly rate they would pay the agency if they were contracting with them, but because a DP is led by the individual contracting with the provider, this figure is less than the provider would charge for private arrangements, and therefore did not cover all of the hours the DP indicated it should.

This is an important issue in relation to the administration of DPs because it suggests that there may be a mismatch between the rate LAs pay carers in the form of DPs for replacement care, and the rate the LA pays the agency if they are the contractor of the service. The consequences of this mismatch were plain to see for Jane, in that she had less care than she expected. It also raises issues for LAs if their assessments state that four hours of replacement care will be funded, but the figure arrived at will only fund three hours.

The limited amount of time that carer DPs comprise is another important issue because it means that participants frequently did not have sufficient time to be able to do things that they wanted to. It also illustrated that carers' assessments were not considering the individual circumstances of participants in the study, as Victoria's extract indicates:

Extract 12: *"I kept on and on and said […] It doesn't give me enough time. I'm stopping in when I should be out because I haven't got time to go anywhere.' Which I haven't. If you're on foot – it's different when you've got a car. When you need public transport, you can't get anywhere. There was ever such a fuss […] I would often just go upstairs for a break but that's no good for me."*

Jane's account corroborated this further:

Extract 13: *"The only thing really that you can do – okay, yeah, you can go and have a facial, you can go and have your feet done and things like that, but most of us spend it doing the shopping. I'm lucky that, like today, I've left my husband. He has to have a Careline, so I've left him with that, and he's got the phone on in case he needs me, but three hours isn't enough to do very much at all. That very first* [DP] *one, I was very happy to get it, because I didn't think I was gonna [sic] get it. Plus, it also depends on the person you're caring for. My husband wasn't keen on having somebody come and sit with him. A stranger. At first, you're thinking, three hours, I can go out and have a coffee, I can walk around the supermarket, but eventually – it seems ungrateful if you like, but it isn't, because you are entitled to it. We are entitled to it. Three hours a week is nothing, is it, really?"*

Jane highlighted how the concept of choice is a complex one. Her husband was not keen on having replacement carers, yet without them Jane would not have had the choice to be able to take a break from her caring role. Her use of the word *entitlement* indicated that she saw her time away from caring as a right.

The blindness to relationality was played out in the data where participants oriented their accounts of DPs in the context of a wider political process, and normative constructs which positioned and reinforced care as the responsibility and duty of family..

7.9.1.3 Sub-theme three: Responsibilising effects of caring

This sub-theme spoke to some of the tensions in caring roles where participants framed a conflict between a commitment to caring where they were viewed and viewed themselves as primarily the responsible care giver. This was set against the challenges of a social and political context in which formal support was limited. This context of care giving against a backdrop where adequate support was unavailable to either carer or cared for cannot be divorced from individual accounts which constructed emotions of guilt, isolation, despondency, and resignation.

Discontinuity of care and negative encounters with paid care staff and agencies, shaped and influenced the extent to which participants made decisions about themselves. Concerns about the quality and nature of paid care, were key to carer wellbeing, and feeling able to take a break from their role. This sub-theme illustrated the interdependency that existed between relationships, responsibility and the impact upon wellbeing and inclusion more broadly. For some participants, the caring role was all consuming and the transactional nature of DPs, as replacement care only, between four to nine hours per week (on average), had little if any effect on participants' abilities to participate in economic and social life.

Jackie, 69, had been caring for her husband for three years. He had a long-term condition which fluctuated in nature. Jackie's account framed the triangularity between herself, her husband, and the paid carer as an important component in her ability to relax and enjoy time away from her role. A discontinuity of care led to strong emotions of guilt, knowing her husband was not keen on the new replacement carer. She felt compelled to return home early from her break, knowing the negative effect this would on her own wellbeing.

Extract 14*: “[...] and stop this feeling of – you feel guilty. Very guilty. I feel guilty at times when I come out and leave him with the carer. Especially now we’ve lost our regular carer. She’s gone off sick at the moment. He did like* [carer’s name], *but she’s off at the moment. Now, I’m in that [...] well, he’s not keen on this one that’s coming at the moment. I said, ‘Well, I’ll try and get back a bit early,’ but then that’s not doing me any good.”*

The quality of interactions with professionals also impacted upon participant wellbeing. Gillian (55) cared for her adult son with complex physical and learning disabilities. At the time of her interview, she had been waiting six months for the outcome of her carer’s assessment. In this extract she illustrated how parent carers face challenges specific to parents:

Extract 15: *“They* [LA] *put you in a guilt trap. We had a lady social worker and there was [sic] times she made me feel totally useless because [...] she said, ‘are you coping with him because he’s kicking off* [at school] *and he’s left’ and I said, ‘because it’s transition this is his way this is what he does when he’s frightened, you know his background, you know what he’s like’. She said, ‘ah well [...] just tell me how you’re coping?’ It’s like she was feeding my brain to say I’m not coping with him you know I’m not coping [...] take him away which it wasn’t that situation but, in the end, it was getting to the point where my daughter came home and said, ‘what’s wrong with you mum?’ I said, ‘I feel I’m being pushed in a corner that I’m not caring for him I’m not coping’, and she said, ‘what after all these years?’ she said, ‘don’t be so silly look at him he’s well cared for’. But I said, ‘it’s the way’, and then when I went to the school she* [social worker] *wouldn’t turn up and it was left with me debating the school and it was left and I think it’s left to all us parents [...]. We are left even* *though they're there as their social workers to help us, we are left as that person who's got to fight. We might get a direct payment, but it's nothing what we've had to fight for. We've had to fight for every single thing we want. I know I'm in for a fight now, because of transition into after school because where I want him to go, they don't want him to go, because he told me I've got to pay, and it's too expensive, and I've been and I'm gonna [sic] fight it."*

Gillian voiced her feelings that parent carers have to *"fight"* for help and support, because there is an expectation that as parents, they should be able to manage their adult children's care needs. The concept of struggle and fight played out in three participant accounts who positioned their sense of responsibility for the provision of care as a shared one between themselves and government. It was the lack of shared responsibility, and recognition from government that lead to frustration.

This was evident in Vicky's account; having given up a career in medicine to become her husband's full-time carer of more than forty year. There was a palpable sense of injustice of a welfare system that turned a blind eye to her efforts when others, in her framing who were less deserving; access welfare without having to contribute. Getting something for nothing in her account:

Extract 16: *"I thought this is ridiculous you know people need things. I've saved the country millions. You know I've done all his doctoring virtually saved the NHS thousands as well you know, and it's sort of it seems very unfair. People who don't save a penny, drink and gamble and smoke, and they get everything paid for and those that save, and struggle get nothing."*

What Vicky's extract represented was an account where she positioned access to welfare based upon deservingness, where carers, based upon this criteria are most deserving of support because of their value to society and what they contribute.

Carers' resource value to society was represented by Jane where she positioned an account of the LA and government, making assumptions about her willingness and ability to provide care. This was set against a desire for help whilst acknowledging that extended families in the UK were often distant from one another, and an economic perspective that care costs money. This is Jane's extract:

Extract 17: "I think they [government] *assume that you'll automatically do it. I'm not sure – it would be nice to have more family involved, but they're all working, and they have different circumstances to when I was working [...]. I know in other countries all the families live together, but that's not possible, is it, because we have a different lifestyle anyway. I have no objection to paying for some of it, but at the end of the day, the government has got the money from somewhere. That's the only problem. There isn't a bottomless bit for the health service or for care [...]. I do resent being told that we're elderly and we're costing the government a lot, when you think we both worked".*

Jane's last sentence in the above extract illustrated her frustration at the way society framed older people who may require care and support, as a drain on resources when there was a view, that her generation had paid into a system that claimed would look after her.

Kate talked about the balance of responsibility between family and state and the challenge of assuming that carers had extended families willing and able to help:

Extract 18: *"I think what they've* [Government] *got to take into consideration you know that my extended family are not interested. We've not seen them in ten years, so we've got nobody to help. We need the government to come in and help us, and it shouldn't be down to grandparents, when they're 70 years old, and looking after somebody, they're going to get pelted by. That's what breaks down extended families, that's what break it down [sic]. My mother-in-law is local, she's 80, she's pre senile we couldn't take my son round because he's* *too dangerous so you know we couldn't. She helped so I could work, when I was working three jobs, when he turned five, and he was headbutting you know you can't, you know."*

Kate's extract illustrated the effect of normative constructs like *care in the community* which assumed that an informal community existed, comprising family/friends/grandparents, able and willing to provide the necessary care and support that adults with disabilities may require. In Kate's case it was very much her and her husband's responsibility to provide round the clock care for their son, with highly complex and challenging needs, which she felt were too complex for her mother-in-law to manage.

Gillian shared a similar position:

Extract 19: *"But when they know that they've got families who are gonna [sic] just get on with it and carry on, they just expect it."*

One participant, Jane, went further and framed caring from a human rights perspective:

Extract 20: *"Do you know, my brother[...], he's had a stroke and it's affected his brain [...] He goes into respite and he said he wants to come home from respite, and they had social workers and all sorts sitting around with* [sister in law's name]. *They said it's* [brother's name] *human right to do what he wants to do[...] It's his human right to come home.* [Sister in law's name] *said [...], 'What about my human rights? Where do I fit in?' 'We send carers in.' 'But is the carer gonna [sic] be there at three in the morning when he wants to get up and go to the toilet? What about my rights to have a good night's sleep uninterrupted? Where do I fit in to all this?' Nobody seems to think about that, do they? What about the carers? My brother with the disability, there were all people around there. He mustn't be left out of it, because somebody is there looking after his rights, but there's no one there looking after the carer's rights."*

Jane voiced the conflict that can exist when the rights and choices of one person may negatively impact upon the rights and choices of another. In this extract she implied that the social worker privileged the rights of the service user over those of the carer. Suggesting that the rights of carers are not given the same prominence as those of service users. This raised questions over the efficacy of a rights-based discourse in care and support conversations where the rights and choices of one can diminish the rights and choices of another.

One participant (Mary) positioned an account of younger generations to her taking less responsibility for the provision of care compared with her (older) generation.

Extract 21: *"I think years ago it was just an automatic thing that you cared for whoever you had living with you. I mean, I looked after my mum for 21 years after my dad died. It's an automatic family thing, but that is eroding. Now, that is eroding, and that's what* [sic] *causing a lot of problems I think, because family members are just choosing not to[...]. You know, you've gotta [sic] step up and take her*[mother] *on board. But the expectations I think are changing. They are changing."*

Vicky agreed:

Extract 22: *"It's very difficult because I think families should do a lot more[...]. I think that families, most families just move away, and don't want to know erm [sic]. When I was in practice, I used to get so cross with relatives who turned up on a Sunday afternoon and left everyone else to care for them. But I think if they* [government] *provided more money, then you could pay for your own help more; and then that would be the best help cause [sic] the families know what help they need more than anything[....]"*

The concept of relationality and the strong emotional bonds that existed between carer and cared for was something that played out in participant experiences of the assessment process.

As the entry point into social care and conversations about help and support for carers; 13 out of the 17 interviewees commented on difficulties they encountered in relation to obtaining help and support with their role.

Theme two illustrated the important role that help and support to the person with care needs can as a by-product promote a carer's wellbeing, for example, in being able to take a break or spend time with friends. No one in the study reported that either a PB for the person they looked after, or for themselves, enabled them to either return to work, or facilitate work with caring (for those participants of working age or who wanted to work).

7.9.2 Theme two: Assessment and support planning practices are barriers to participation and inclusion.

Theme two voiced accounts from interviewees who spoke about the challenges they experienced in gaining help and support from adult social care departments. These challenges were often described in relation to their first encounters with adult social care, through to assessment and support planning conversations, that limited what carers were able to do with their DPs. No participant in the study was given a choice in how they received a PB. All eligible participants received PBs in the form of a DP. Only two participants out of 17 were offered any choice in what they could spend their DP on.

7.9.2.1 Sub-theme one: Access to help is problematic

The majority of participants (13 out of the 17) described the assessment process as frustrating, difficult to understand, and unclear how it was intended to help them to meet their needs. Many, (15 out of 17), reported being instructed that their DP had to be spent on replacement care, in the form of a sitting service. This limited the intended effect that DPs will promote a carer's wellbeing as the following accounts showed:

Jane (64) cared for her husband with a chronic illness for three years. His needs fluctuated which meant the intensity of her role shifted over time. She had been in receipt of a carer's DP for 18 months at the time of interview. In the following extract, she reported the challenges she faced in obtaining a carer's assessment. She identified how the carer's assessment could not adequately capture the impact of caring on her life, because the assessor did not meet her husband. Her husband's assessment of need did not take account of her needs either.

Extract 23: *" I know this is about the carer and not the other person, but they don't know what my life is like if they don't see my husband. I asked this lady about – I said, 'I understand I'm entitled to four hours free time a week,' and she said, 'No.' Now, I knew that wasn't true, so I think through* [names support worker]; *I contacted the* [carers charity] […] *Then she rang me up and said, 'I understand you want a carer's assessment.' I said, 'Well, I'm told that I should have had it when you were assessing my husband' […] they didn't ask about me, about what I needed."*

The challenge of accessing an assessment is corroborated by Jackie (69) who looked after her husband with a long-term condition (LTC) for three years. Jackie was unable to recall whether she had received an outcome following her carer's assessment. In this extract she highlighted her surprise that her carer's assessment was not face to face:

Extract 24: *"There's a lot of toing and froing, because I think you have to be allocated to someone, and then they ring you back. There's a lot of phone calls involved. I was amazed that nobody came down to see me [...], had my assessment over the phone [….] When he was in hospital, that's when the social worker there offered me a carer's assessment, but I've not* *seen anybody here* [at home] *that has actually offered me a carer's assessment. I've had to put myself forward for it".*

What Jane's and Jackie's extracts demonstrated was that they felt it was difficult for the assessor to fully grasp how caring affected their ability to have a life of her own, if assessors did not meet the person being cared for. In Jackie's case she did not have a carer's assessment whilst her husband was in hospital. Jane's carers assessment was conducted over the telephone.

Denise, 32, had looked after her mother with Parkinson's disease for almost five years. She cared for her father up until his death, and then moved to live with her mother, to look after her full time. She had received a DP for just a few months but stopped the payment because replacement care neither met her mother's nor her needs. In this extract she talked about her repeated attempts to request a carer's assessment, and a sense that she felt she was not being listened to by the person on the other end of the telephone:

Extract 25: *"The original* [carers assessment] *one 'cause [sic] I have been in touch with them a couple of times since then, the original one I think was an initial conversation about what my caring role entailed, and it's changed over the years, obviously mum has got progressively worse, and I was supporting dad looking after her, and then I was supporting mum on her own. Even though I said I got your number from* [names local carers charity] *they said, 'oh we'll send you some leaflets about, you know support in your area' and one of them was* [local carers charity]. *So it was sort of a vicious circle, of going round, and that was all they really offered me at that time […], they didn't really know quite what to offer me I don't think. I came away thinking, I was a bit despondent about it, and then when I got this information about* [carers group], *I told them that ' I can't attend that* [carers group]'. *I find that a bit frustrating, so I thought aah sod 'em"[sic].*

Denise's frustration was evident from her account that she felt she was not being listened to by the assessor. Denise was already familiar with support provided by her local carer's centre and informed the telephone assessor. Only to have that information repeated to her. She also implied that the telephone assessor was not clear on what support they could offer her.

Frustration, confusion, and complexity were terms used by 11 participants to describe their experiences of the carer's assessment process. Caroline, 65, had her own health issues, and looked after her mother with Alzheimer's disease. She gave an account that unless you lived with the person you looked after, then no help from the LA was forthcoming. She decided not to pursue her carer's assessment based upon her experience:

Extract 26: *" I know at one point I filled in a form for a carer's assessment and sent it off, and then I didn't hear anything, and was obviously waiting to hear. Then I think* [local carers group] *become involved and they said about* [sic] *carer's assessment and I said, 'I've done one of them,' and she said, 'What did they say?' I said, 'Well, I've not heard nothing* [sic] *yet.' 'Okay, we'll chase it up.' Then she come* [sic] *back, and she said, 'No, they didn't get it. They've got no knowledge of it.' I was like, 'Right, okay.' 'You need to do another one.' 'Right, okay.' Then she said, 'But the only thing is[…]' because I'm not there caring, because Mum's got carers, she said, 'I doubt you'll get anything, so it's probably not worth your while doing it.' I couldn't be bothered...so I gave up."*

Caroline gave up on pursuing her carer's assessment beyond this point. The experience she described of completing an assessment, and the LA claiming they had no knowledge of it and then being told that she probably would not receive any help acted as a deterrent to support. The delay in receiving a response from the LA, coupled with the claims by the carer's charity, created an impression that access to support is unavailable for carers who do not live with the person they look after.

For one participant, negative first encounters with the LA did not always act as deterrent. Jack was spurred on by the difficulties he encountered, in a bid to understand what his rights were.

Jack, 63 looked after his wife with an LTC and breast cancer for six years. At the time of the research interview, he had not received an outcome from his carer's assessment. In this extract he highlighted the confusion that existed for carers over whether or not they had been assessed and the lack of clarity that existed around the types of support that were available:

Extract 27: *"I thought I'd had a carer's assessment. That's what I asked for. I went through a long telephone interview. I've just dug this out. It's a letter dated in March and it's, 'Enclosed is a copy of your emergency plan and your own carer's emergency card.' I carry that in my wallet if I have a bump, so they know* [wife's name] *here. When I've read through this [...] it said, 'The offer of a carer's assessment is declined.' Now, I put that on because I thought I'd already had a carer's assessment. That's the one they should […].'This carer's emergency plan has been written following a carer's assessment."*

Jack reported that he later tried to find out more about his entitlement to a DP via the Council's web pages and attempted telephoning again to be informed that he could have a DP, but it could only be used to pay for someone to replace his care. His extract pointed to the confusion that surrounded the use of language used by his local council to describe what a DP could be used for:

Extract 27: *"Some of my questions I thought would answer [sic] on various departmental web sites, but not correct. All I have managed to find, is that ' carers direct payments can be used to provide the needs established as a result of an assessment.' Clear as mud that is. I anticipate most carers will be told, like I was, that you can employ someone to sit with the* *cared for person, so you can access the community etc. But are not told what that means exactly."*

Later in the interview, he returned to the topic of DPs:

Extract 28: *"With the direct payments, it seems to me that the process is amorphous, and akin to putting your hand into a black bag of orange jelly, to try & find the blob of lime jelly that someone from social services has stirred into it - although they can't remember if they actually added the lime jelly!"*

Jack questioned the meaning and clarity of language used by the LA, to describe how a DP could help support him in his role. Suggesting that the information presented either over the telephone or in written form, via a website did not clearly state how DPs benefitted carers. What Jack illustrated, was how language presented barriers and obstacles to gaining support; implying almost a sense that the LA may not always be clear themselves on how DPs are meant to support carers. This was evidenced in his questioning of the meaning of *accessing the community* which is one of the indicators of wellbeing defined by the Care Act (2014).

Another challenge with the assessment and support planning process, which was reported by participants, was the apparent inability to consider how carers were able to balance work with caring, or their wish to work, as the Care Act (2014) guidance suggested must be considered during an assessment.

Dot, 52 had looked after her son with severe autism for 21 years. She highlighted the tension that existed for many parents in her situation where the service and support to her son, dictated the extent to which she was able to work:

Extract 29: *"Really, I'm looking for a job to fit in around the care that's already in place, when really, I should be looking for care in place, to work around a job. In a sense."*

Another parent carer in the sample corroborated Dot's claim, that careers were difficult to obtain and/or maintain when you had a full-time caring responsibility. Kate (44) had been a carer to her son with severe autism for 21 years:

Extract 29: *"Well I had a job I loved, loved it, it was a good job, it was a fun job, it got your brain working, but I had to give that up to be my son's carer, and as bad as it sounds, it makes you quite bitter because you don't ask for this life […] I couldn't do both."*

What came through from these extracts was the lack of clarity over the purpose and process of carer's assessments. It was not always obvious to participants, if there was a criteria for an assessment of their needs, and if they had received an assessment, it was not evident what followed as a result.

Another challenge with the assessment and support planning process appeared to be the speed at which the LA was able to respond to calls for help. As well as describing the difficulties participants encountered accessing assessments; eight participants described accounts of help only coming at crisis point. These participants expressed feelings that they had to prove they were struggling or unable to cope with their caring role, before an assessment was forthcoming. This was evident from Dot's account, who cared for her adult son with severe autism. She had moved to a different LA area, and reported that she was told, both her son and she would have to be reassessed. The amount care and support her son had received from a different LA was not portable to the receiving LA :

Extract 30: *"I need my carer's assessment. I've got no funding. I'm going mental at home. Told them about the college. I said […] 'I need some support. I need to get him doing stuff.' She kept saying to me […] just kept fobbing me off. She'd say, 'Oh right, well your case has just been handed over to me from this other woman. We need to liaise. She's not in today, but she'll be in on Monday. Can you ring back next week?' I'd ring back next week, 'I haven't* *had a chance to talk to that woman, so I haven't been able to take over* [son's name] *case.' Then I'd ring again, 'Oh, she's not in. Her car has broken down.' Every week – or I might leave it a fortnight, because by this time now, I'm getting just mentally drained and I don't really want to deal with this anymore, but I know I have to. I keep ringing and ringing and I'm getting told different stories. 'The manager has got to read it. No, she's not in, she hasn't had time to read it.' I was getting fobbed off and I was fed up to the back teeth with it. I still hadn't had my carer's assessment. She just kept fobbing me off. By Christmas, I had a breakdown. I'm on the phone to this woman […] I was crying my eyes out on the phone to her. I said to her, 'I cannot deal with this anymore. I can't talk to you right now because I am just completely and mentally spent. I'm gonna* [sic] *be putting the phone down right now because I've had enough'[…].the social worker and her manager came to see me in person. I think they realised I'd been pushed over the edge."*

When you compare Dot's extract with Caroline's (extract 26) you see again the issue of delay emerging. In Dot's case the delay was not caused by the LA having no knowledge of her carer's assessment, rather the delay was attributed to the unavailability of a social worker to assess their needs. Delay prevented people from accessing help, by slowing down their interactions with the LA and in Caroline's case, led her to give up on the process, and Dot reaching breaking point before help was forthcoming.

Help only coming at crisis point was reiterated by Kate, 44, who looked after her adult son with complex physical and intellectual disabilities. She also lived with her own long-term chronic illness. She had had a DP for approximately three years but had not found the payment had had much effect on her life, in part because she and her husband were unable to find carers to help them. Here she talked about hitting 'rock bottom', before she got a carer's assessment:

Extract 31: *"Me and my husband we sort of hit rock bottom, erm,* [son's name] *wasn't sleeping so we weren't sleeping or eating. I was in a really dark place, and then we did phone up duty to come and get him, and at that point I was offered a carer's assessment. We were never given, or I've only just found out actually, that we're entitled to copies of our carer's assessment, as my health, physical health deteriorated. I had another carer's assessment at my request three years ago, they lost the paperwork […] But they did increase our direct payments, but they couldn't increase because we couldn't find the staff. The only time I was reassessed was when we said 'enough is enough now, I'm ready to pack my bags'. It was demeaning, 'so you're saying you can't deal with your child. So you're saying you can't do this?', and you have to prove it, you almost have to get down on your hands and knees and prove that you can't cope."*

Kate provided a context for her caring role within the confines of parenting, which illustrated the challenges she faced as a parent carer. Her extract corroborated Gillian's (extracts 15 and 19), where LAs can make assumptions that parents should continue to provide care for their adult children, even though there is no legal compulsion to do so. Although, as Kate alluded to, children who become adults are still your children, and the sense of duty and love made it extremely difficult to say you were struggling. The emotional effects could be significant as the next extract illustrates.

Victoria, 77, lived with, and looked after her elderly frail mother. She had been in receipt of a carer's DP for two years and used the time it afforded her for short trips out of the house. The challenge for Victoria, like other participants was the time limited nature of the DP, which she suggested make it difficult to go very far, because she was worried about being late for the replacement carer. She talked about feeling desperate for help, and the impact it had on her mental health. She highlighted how carers are not always in good health themselves, which illustrated the reciprocity in caring relationships; that carers can both give and need care and support themselves. Her frustration came through strongly in this extract:

Extract 32:*"Well, often resentful. I don't do it because I want to, but I do it because it's my duty. I'm not unkind to her[....] I do everything I can for her [....] I'm not so bad now, I think because it's summer I'm not in so much pain, but in the winter[...] I remember one morning walking over the sea wall and the tide was in, and it looked very inviting. I thought, 'listen, I gotta [sic] get some help'. I couldn't cope [...] I told them 'the payment doesn't give me enough time'. I rely on public transport so there's no point in going out. Sometimes I use the time to go upstairs and read a book, but it's not the same as going out and being with people [...] if she* [mother] *knows I'm upstairs, she'll shout for me, even though she's got the sitter with her. It's just not a break for me."*

Four participants used adjectives such as *fighting* and/or *battling* to describe accessing help and support. Jane cared for her husband with a chronic illness:

Extract 33: *"Fight is the word really. It's horrible to say it, but fight is the word, because we're pretty sure that if we didn't, we wouldn't get anything, because they just deal with those at the end of the phone."*

Jane's use of the pronoun *we* was interesting. It was not clear if she was referring to herself in the context of her marriage, or if she was referencing carers as a collective noun. Fighting for help and support was echoed by Caroline who looked after mother with Alzheimer's disease:

Extract 34: *"I've fought. Everything I've put in place, I've done it. I've done it through the internet, through basically turning around and saying, 'I need help. I'm not coping with this."*

Once participants were able to access carers' assessments, the next hurdle identified in the analysis of interview data was the extent to which those who were found to be eligible for a PB were given either any choice in the mode of administration, i.e., DP, part DP or managed service, and/or choice over what the money could be spent. No participants in the study were given a choice over the administration of their PB. Of those found eligible, all were told they would receive a PB in the form of DP. Two out of 17 interviewees were offered a choice in how they spent their DPs.

7.9.2.2 Sub-theme two: Lack of choice over how DPs are spent

Once participants entered through the front door of adult social care, and were found to be eligible, the next challenge appeared to be finding that there was limited, or no choice in how they could receive a PB (either as a DP, indirect payment, or managed service), or choice over how DPs can be spent in order to meet their needs. A picture emerged of a 'one size fits all' approach to the provision of support, for participants in the study. All participants, except two (Dave and Jane), reported that they were told they had to spend their DPs on replacement care, in the form of a sitting service. As many of the accounts illustrated, there was a mismatch between the support offered, and the support needed. There was an evident lack of personalised support solutions for carers, with accounts of delivery illustrating a service rather than needs led approach.

Once a DP was agreed, further challenge was experienced in relation to the complexity of the administration and management of the DP process. Either, because it was difficult to navigate around DPs as a bureaucratic exercise, or because it made the caring role more stressful and burdensome. Dave looked after his wife with Parkinson's disease and Lewy body dementia. Here he talked about the challenges of making sense of the regulations around employing someone with your DP. In fact, what he was explaining in extract 35 was the system that regulated his wife's DP, which illustrated the confusion that existed between systems that administered one DP process for the carer and another for the cared for:

Extract 35: *"The first 6 hours I had was awarded in December 17, but I never used any of it till [sic] April, because the government set out this workplace pension rubbish, so I couldn't employ anybody under state pension age, unless I set up a pension for them. The people that handled* [wife's name] *money – which is* [third party broker] – *I asked them, 'Do you deal with pension deductions?' 'Oh no, you have to do that.' Well, how on earth am I gonna [sic] work that out? I then got contact from HMRC saying, 'We've been advised you employ so-and-so and you've now gotta [sic] set up a pension,' and everything like this. Sent me reams of paper. I sent them an email and said, 'We're not employing anybody'. It's too much aggravation. I can't work all this out. My wife certainly can't. As a consequence, we're now not employing anybody, so 'thank you very much, we haven't got any care at all', and left it at that. Obviously, never got an answer".*

Dave alluded to the bureaucratic nature of DPs, and the various people and organisations involved in managing the DP process, being problematic. In his case, they took the decision to stop the payments because of the stress it invoked. The DP process may be confusing for carers, but in the next extract Denise suggested that it may not be clear for professionals either. Here Denise talked about having to help her social worker with the costings for her DP, being used to pay for replacement carers:

Extract 36: *"It took so long for him to work out the payment. I had to do all the finding out of the costs involved, then get to him, and he had to do the paperwork. Then he went on holiday, I don't know what happened then. I took my bank details into the office in [names town], and* *he then had to confirm them again, cos [sic] he'd lost them or something, and it took so long I got so despondent in the end."*

For the third time we see delay emerging in Denise's account of the social worker losing her bank details, and this leading to feelings of despondency on her part. The idea that PBs promoted carer wellbeing or empowered carers to have a greater sense of control and choice over their ability to care, and to determine what and how their needs were met, were not borne out by the qualitative findings. Findings from the analysis of interview data suggested that assessments were difficult to access; they are not routinely offered as part of the service user assessment, and no account was taken of the participants' ability to maintain, or access employment, education, and leisure, which were a legal requirement of a carer's assessment.

However, two out of 17 participants (Dave and Jane), gave an alternative account by suggesting they were given a choice over how they could spend their DP, but even when Dave suggested he was offered a choice, the response from the assessing social worker implied otherwise. Jane was told that she could pay a family member with her DP but again, it could only be spent on replacement care in the form of a family member sitting with her husband. Here is Dave's account:

Extract 37: *"I can recall her* [social worker] *saying something about, 'You can spend the money on what you like. As long as you send in the right documentation, you can more or less spend it on what you like.' I said, 'We'll have a holiday then.' 'You can't have a holiday' she said [...] But as regards my money, all I've been told about my money from memory is they're* [Social Services] *struggling, but it is purely for replacement care and I can't use them to do any manual work".*

Jane used her carers DP to pay her son to sit with his father:

Extract 37: *"They did say that we don't have to stick with* [sitting service]. *I have paid my son. He's sat with* [husband's name] *for quite a while. As long as you keep a book of receipts and things. If he's come over, I've paid. They say you can pay anybody. A family member, anybody, any friends, neighbours that can come and sit."*

Yet when Jackie asked if she could pay a family member to come and sit with her husband, who they both trusted, the answer was no:

Extract 39: *"But I can't remember exactly what they said, but they said it had to be spent in such a way that I was relieved of care. Well, I thought it was a bit stretchy* [sic], *that I couldn't use family, so I have to use somebody who I can get a proper headed receipt from".*

There appeared a lack of consistency in the guidance that carers in the study received about ways they could spend their DPs, but overwhelmingly the majority were clear they had no choice as Kate described, who cares for her adult son with complex physical and intellectual disabilities:

Extract 40: *" No, there was no choice it was we were just literally told you're getting 9 hours per week and this is to pay for care and care only."*

The situation was made doubly difficult for Kate, because her carer's DP took no account of the fact that her son required two to one care, and therefore, she in effect had to be the second carer because the carer's DP funded only one carer:

Extract 41: *"No because it* [DP] *was on a one-to-one basis and my son is two to one so I was the second person, it actually put more pressure on me."*

Kate's extract illustrated the problematic nature of assessing the carer without considering the needs of the cared for at the same time. In Kate's case the carer's DP was rendered meaningless, because of her son's complex needs.

Two participants questioned whether paid carers from sitting services had the skill and knowledge to care for their adult children safely, Kate again:

Extract 42: *"But it's down to me to find the carers in the first place and it's hard to do when you've got somebody like* [son's name] *and you're getting get head butted you're gonna get hit very very [sic] aggressive extremely aggressive you know[...] a lot of agencies won't help."*

This is echoed by Gillian:

Extract 43: *"I think that's my problem with* [son's name] *I don't feel like I can trust people with his health, and I worry that they're not gonna [sic] be at that right time doing his stoma doing this and it does worry me [...]"*

From the extracts presented in the preceding pages it showed that separate carer's assessments appeared not to take account of the individual circumstances of participants and in some circumstances, like Kate's made the caring role much harder, because her DP meant she could not leave the home. Moreover, the concept of relationality was an important element in the context of the relationship, between the carer and paid carer. Gillian expressed concern that the replacement carer may not be able to cope with her son's level of need. If the person being cared for is not willing or cannot safely be left with replacement carers from a sitting service, then the carer's DP is less likely to have a positive effect, because of the anxiety and lack of confidence the (family) carer may have in the skill and knowledge of the replacement carer.

One sample participant questioned the intention and purpose behind carers DPs. Jane challenged the assumption that DPs promoted choice and control:

Extract 44: *"It's (DP) a bit of something really, just to keep you quiet. Isn't it really? Just a token thing to keep you quiet".*

Jane framed the DP system, as one that had a hidden agenda or meaning. One that was designed to buy your silence, so that you continue to provide care; an unspoken, unwritten contract between carer and government. This counter narrative of PB as bribe, rather than promoter of wellbeing and inclusion, demonstrated how Jane challenged the dominant discourse that families should and would accept responsibility for the provision of care.

The concept of 'hidden' agenda was given voice in accounts, where participants described the frustrations they experienced in obtaining help and support. Delay (whether through lost paperwork, no social worker allocated to the case and/or telephone calls not returned) in this context served a purpose, because it managed the demand on an overstretched social care system. Complexity of processes characterised accounts where some participants gave up (Denise and Caroline), and, in Dave's case, handed back his DP, because of the stress it invoked. Dave's social worker spoke of Social Services financially struggling, as a context to the limited way in which Dave could spend his DP. Participant accounts gave voice to ways in which they were kept at arm's length by the adult social care system. It kept participants out of the system, therefore, acting as an unspoken form of rationing in the same way that eligibility for support acted as a form of rationing.

The one-size-fits-all approach to carers DPs, for participants in the study presented obstacles that affected their ability to participate in economic and social life. Once again, this one-size approach spoke to a form of unspoken rationing because all participants received the same, or similar responses irrespective of individual need. This presented issues, particularly, if the cared-for did not want to be left alone as the following extract from Denise suggested:

Extract 45: *"He* [social worker] *suggested that I could use the direct payment to continue doing some voluntary work, that I was doing at the time, that if mum had somebody come and sit with her and talk to her for a couple of hours. It would allow me to get out and do something for myself, and I thought 'yeah ok I would try it,' and it was all set up eventually, hoops to go through etc. Then it didn't work out, mum's very anxious about people that she doesn't know in her house, when I'm not here […] But for one or other reasons we stopped it after three weeks. It wasn't so much of a direct payment, it was more of a one-off direct payment, that just went to pay the bill at the care agency that supplied them, so it didn't really work out".*

Denise gave the impression that if replacement care does not work out then nothing else is offered to the carer. There was no alternative support plan to consider how else a DP could be spent in ways that supported her to have some time to herself.

Dave's extracts showed the limiting effect of a sitting service in meeting his need because the replacement carers could not do anything practical to help his wife:

Extract 46: *"I recently had a carer's assessment which led to my wife being subject of a review. I was told, amongst other things, that the formal carer who covers my absence is not permitted to help my wife in any way. I asked for clarification if they could help my wife from the couch and to the toilet, maybe make a sandwich and a drink and was told 'no, they are just to fulfil a sitting service to allow me to have time out.' I forgot to ask if my wife fell could they call for help or not[…] what is the use of having someone sit and look at my wife, do nothing to help her and expect me to be happy with that service. I have said that all my hours under the carer's direct payment, 12 per week, should be taken from me and given to my wife so when she has a carer from her monies, they can help her in these needs. I do not have a* *need for a direct payment if I cannot be assured the replacement carer is behaving as I would if I was there. Rant over."*

Later in the interview, Dave implied an attempt on the part of the LA to offer a one size fits all for carers, as a means to save money:

Extract 47: *"I have told the social worker that there is no way that I would leave my wife with anyone who was not allowed to help her[…].so, give my hours to* [wife's name] *so she can employ the same people and gain the needy care and assistance she obviously needs. If they are still minded awarding me hours / money, then it is unlikely it would get used for the reasons above. Perhaps this is a subconscious ploy to save money?"*

In this extract, Dave constructed an account of a hidden meaning to save money by making the process of carers DPs bureaucratically complicated and practically prohibitive. Such that carers either stopped their payment because they did not meet their needs or the needs of the cared-for, or the process is overly complex that it contributed to stress and anxiety, rendering the exercise in promoting choice and control meaningless. Again, with Dave's extract, we saw for the fourth time how participant accounts expressed experiences that spoke to delay and deterrence on the part of the LA, i.e., access and support being made difficult, such that participants rejected offers of support because they were not helpful or made their caring role more challenging. This spoke to a form of rationing on the part of the LA; rationing by deterrence, because access was made difficult. Rationing by delay, because participants were made to wait long periods for assessment and support and rationing by overly complex systems and language that were difficult to navigate and lacked clarity and transparency.

7.10 Summary

Findings from the analysis of semi-structured, qualitative interview data suggested that PBs, in the form of DPs, delivered as a time-limited replacement care service had a limited effect in promoting participants' wellbeing, and facilitating their ability to have a life of their own alongside caring, in part, because of the transactional and individualised way in which the DP process was delivered for participants in the study.

Participants, with the exception of two, were neither given a choice about the administration method of their PB, nor choice and control over how their DP could be used to pay for things that could promote their wellbeing or participation in economic and social life. PBs were viewed as a service- rather than a needs-led offer, and there was an assumption that all carers in the study had the same need (to take a short break from the caring role), and this need could be met by a replacement care service. This presented significant challenges for those participants who were unable to work, or would have liked to work, because the DP process could not support their economic wellbeing.

The transactional nature of the assessment and support planning process took no account of the relationality that existed between participants and the people they looked after. For many participants, their DPs, as a replacement care service, meant very little, if the person they cared for either did not want to be left with a paid carer, or their level of need meant the carer could not leave feeling confident that the paid carer could safely manage care. Key to participant wellbeing was a sense that replacement carers were confident and knowledgeable about the condition of the person being looked after, and that they were able to build a rapport with both the carer and the cared-for.

Moreover, the individualised way in which a carer's assessments were conducted, particularly those over the telephone, presented barriers for participation because they did not take account of the interdependency that existed between the needs of the carer and the person they looked after. Needs were inextricably linked, and support for the cared-for, as a by-product, may also support the carer. It was not just the carer’s DP that could facilitate this.

A number of participants talked about the use of language as a barrier in terms of its inaccessibility and the challenge of navigating your way around a complex system, which, for some, was not designed to help.

A small number of participants challenged the veracity of the Care Act (2014) rhetoric, that DPs could promote their wellbeing. Two participants implied that the Act’s true purpose was to save money, by calling on families to do more and offering them a token sum to buy their silence. This was positioned as an injustice for two participants, who cited their needs from a human-rights perspective, and suggested that an injustice existed in the way in which their contribution was not valued by the government, yet their contribution to society was significant.

Participants who voiced their frustrations about an ineffective system gave voice to ways in which rationing occurred beyond the transparency of nationally determined eligibility criteria. Accounts of delay, complexity of processes, language, and one-size-fits-all DPs offered, all had a rationing effect. It limited, and/or stopped participants asking for help because it contributed to stress and anxiety in a way that made the DP system untenable for them.

These findings suggest that the Care Act (2014) is ineffective in its intention to promote the wellbeing of carers through the use of PBs. The findings raise important questions not only about the efficacy of the Care Act (2014), in helping carers to participate in economic and social life in the same way that non carers do, but, also, about the wider unspoken agenda that PBs are enacted in such a way that they exclude, rather than include, carers in society.

These important questions will be debated in the next chapter, which merges the findings from all three phases of this thesis in order to address the research questions, specifically.

Chapter 8 – Discussion and conclusions

8.1 Purpose of the thesis and research questions

The purpose of this thesis was to explore social inclusion and participation by assessing the extent to which the Care Act can promote the wellbeing of carers through the use of PBs. The thesis sought to achieve this by:

1. Examining the intentions behind PBs as a policy solution to the problem of caring
2. Identifying if PBs have impacted upon reported levels of subjective wellbeing across England
3. Exploring insights from carers about the difference that PBs are making to their lives

The assessment of the claim was measured in the quantitative phase (two) of the study using ASCOF and SALT performance data, and regression analysis was applied to the 2018/19 SACE survey data, to test the hypothesis that PBs improve carers subjective wellbeing. In the qualitative phase, an assessment was based upon thematic analysis of interview data with carers (phase three), and a WPR analysis of the Care Act's policy guidance (2014) (phase one).

The study sought to answer the following questions which corresponded with each of the three research phases:

- Phase one: *The Policy intentions*: What are the intentions behind PBs as a policy solution to the problem of caring?
- Phase two: *How the intentions played out*: Do PBs improve carers subjective wellbeing scores across England?
- Phase three: *The lived effects of the policy intentions:* What difference do PBs make to carers lives?

This final chapter merges findings from the analysis of each research phase in this thesis, in order to answer each of the research questions. Mixing findings from both the quantitative and qualitative elements of the research offers a more robust discussion, because each theoretical perspective used provides a different lens through which to form a judgment about the effectiveness of PBs on promoting carer wellbeing. The differing theoretical perspectives informing each phase of the research opens up the possibility to reveal possible contradictory positions between the policy intention and practice reality.

8.2 The intentions behind PBs as a policy solution to the problem of caring

8.2.1 Phase one: The policy intention behind PBs for carers

Three policy intentions were identified in the Care Act (2014) guidance :

1. Give carers parity of esteem via access to assessments based on the appearance of need.
2. Give carers a greater sense of choice and control through outcomes-focused assessment, and support planning conversations.
3. Promote wellbeing (encompassing participation and inclusion) through the administration of PBs for carers who are found to be eligible following a needs assessment.

Carrying out a WPR analysis of the intentions behind PBs as solution to the problems that carers face has revealed that the Care Act (2014) guidance reflects a responsibilising agenda. Findings from the WPR analysis indicate that carers are problematized as people who lack wellbeing, because they are unable to balance their own lives alongside caring. PBs are framed as a policy solution that eases their burdens. The problems associated with caring are seen primarily as an individual’s responsibility to solve rather than viewed as problem for government. However, it is very much a problem for the government if families stop providing care.

Depicting caring as a problem for the individual to manage can be seen in the way that PBs are described in the guidance. Examples of their use, in ways that develop skill and knowledge, such as moving and handling courses, stress management and relaxation emphasise what the carer can do to help themselves, rather than considering how the PB can be used to facilitate their participation and inclusion, such as getting back into the workplace or education.

The emphasis on this individualised description implies that it is the carer who is to blame for their inability to cope, or for their high stress level, rather than there being a responsibility on the state for the amount of care that is being asked of families which negatively affects their health and inhibits their ability to work. This was evidenced in findings from the thematic analysis of semi-structured, qualitative interviews, where two participants talked about their desire to work but could not because there was insufficient care available to support the person they looked after. Moreover, evidence from the narrative synthesis corroborates this view with no evidence presented that PBs for carers increase their capacity to undertake or maintain paid employment. One of the barriers to carer participation is the insufficient supply of social care for the disabled adult (Larkin and Dickinson, 2011; Seddon and Robinson, 2015).

Problematising caring at the individual level positions PBs as a quick fix. They are viewed as a payment that can solve the problem of wellbeing. Wellbeing is characterised as something that can be improved through one-off activities that will help you to cope with caring, such as improving coping skills through a counselling course, or developing caring skills through manual handling courses. The assumption behind this is that increasing carer knowledge you increase carer wellbeing.

This framing implies that the intended purpose of a PB is not to support you to have your own life, but rather to keep you caring so that the state does not have to. PBs are more about a transaction than they are about a carer's participation and inclusion in economic, social, and cultural life. The transactional nature of the PB process was reflected in the analysis of interview data, where participants spoke of the lack of choice they were given over how they received the PB, and, also, in how it could be spent. This view was echoed in the narrative synthesis, where papers described the paradoxical nature of framing personalisation for carers in relation to choice, because theories of personalisation simultaneously enable and constrain carers' lives (Arskey and Glendinning; 2007; Larkin and Mitchell, 2016).

Having a life of your own assumes that carers conceive of themselves as individuals, independent of the person they care for, when the evidence from the qualitative findings and empirical evidence suggest otherwise. Participants in the study expressed how their own needs are mediated through the needs of the person they support and the nature and quality of the relationships and support they receive from professionals and care providers. Being able to do things that you want to do relies upon the right sort of care and support being in place for the cared-for person. If that is not in place, then a carer's PB made little, or no, difference for participants in the study. This is also supported by the narrative synthesis of literature, where significant variations were found in the manner that PBs were allocated to carers (Mitchell and Glendinning, 2017; Seddon and Robinson, 2015; and Woolham *et al.,* 2018).

The qualitative findings corroborate the broader contextual factors that shape choice and control for carers found in the literature. Several studies show how the nature of the relationship between carer and cared-for, availability and affordability of paid care to support the ill and/or disabled adult, and organisational and professional practice shape the extent to which carers are able to participate in economic and social life, more so than a PB (Arksey and Glendinning, 2007; Larkin and Mitchell, 2015; Rand and Malley, 2014). Where PBs are shown to increase choice and control, these concepts are narrowly defined and not related to broader life opportunities such as employment or education (Jones *et al.*, 2014; Moule *et al.*, 2014; Rabiee, 2012; Woolham *et al.*, 2018).

The declining trend in the number of carers assessed and supported by CASSRs across England between 2014 and 2020, shown if phase two findings, suggests that fewer, rather than more, carers are being identified and supported since the introduction of the Care Act (2014). Those carers who are assessed are much more likely to receive advice and information as a result of assessment rather than a PB, which calls into question the efficacy of the assessment and support-planning process in facilitating carer choice and control, than theories of personalisation would imply.

The individualist discourse in evidence in the policy guidance, is set against another, competing discourse that can be seen in the way in which collectivist accounts of families and friends being viewed as the better carers. First, is the individualist versus collectivist ideological framings of caring (Dalley, 1996). Individualised accounts are evident in the way that the guidance positions PBs as a means to independence, autonomy, choice, and control over carers’ lives. This conflicts with collective accounts of caring, in the guidance, where it talks about the importance of relationship and reciprocity as being successful components of caring. Families are positioned as ‘better’, carers and people are encouraged to look to their natural networks and communities for support, first and foremost, rather than to the state for support. It also conflicts with the new duty in the Care Act (2014) to offer carers a joint assessment with the person they care for. This is in line with the policy guidance attached to the Care Act, called: ‘Whole Family approaches to assessment’ which are designed to understand the needs of the family in the round rather than individually. The evidence suggests that joint assessments reflect the reciprocal and relational aspects of the caring role in that the needs of the carer are often linked with those of the cared-for. Yet, the empirical evidence challenges this position and indicates that joint assessments do not always lead to better outcomes for carers. Seddon’s and Robinson’s 20-year longitudinal study of exploring tensions and dilemmas in carers’ assessments with, social care practitioners, found joint assessments tended to privilege the service user’s perspective over the carers. Carers’ needs were considered more in relation to what they were willing and able to do in support of the service user and not any needs the carer had as an individual in their own right. This was corroborated by Rand and Malley (2014); and Brooks *et al.* (2017).

The theory that whole-family approaches to assessment lead to better outcomes for carers is similarly not supported by the secondary analysis of performance and survey data. SALT findings showed that joint assessment were less likely to lead to a carer receiving their own PB compared with a separate carer’s assessment.

The concept of autonomy, as it relates to self-determination, conflicts with the notion of care as a reciprocal act. To frame care in terms of individual freedom and rights forgets that things the carer might want or desire, such as a job, or time to themselves will impact upon, and, potentially, be at odds with the self-determination and autonomy of the cared-for person. This played out in the qualitative findings, where some participants expressed a desire to have more time away from their caring role, but the person they cared for did not like, or would not agree to, being looked after by a stranger. Freeman (2019) suggests that the concept of self-determination is part illusory, because we must exercise freedom under the constraints of others. Therefore, there are practical and moral limits on the reality of individual autonomy.

Instead, he suggests we consider the values of self-determination in the context of wider values of social justice, and not simply at the level of the individual.

Second, is the conflictual way in which theories of care are orientated in the guidance, i.e., EoC versus PoC. EoC, with its emphasis on family care being better care, because it is loving, dutiful and responsible, and PoC, because the guidance acknowledges that caring can impact your life in ways that non-caring does not, such as economic and social inclusion may be comprised. Competing ideologies of caring are also evidenced within the guidance. Theories of care which frame effective care as a loving act between individuals has enjoyed a position of hegemony in academic discourses over the last 25 years (Conradi, 2020; Gilligan, 1993; Noddings, 1992).

In contract, political theories of care (PoC) receive less attention in the academic and policy literatures to explain how caring impacts upon peoples' lives (Conradi, 2020; Tronto, 2017). PoC frame the conditions necessary for effective care giving at a macro, societal level, and, therefore, construct caring as an activity that can disadvantage some groups more than others. This was shown in the genealogical analysis of caring where the evidence suggested that factors such as socio-economic status and gender have a greater bearing on a carer's ability to participate in economic and social life. Factors that are beyond the individual's control. For example, the gendered nature of care renders caring an activity that disproportionately affects women more than it does men, because women do more of it, and the normative constructs used to characterize caring as loving, empathic, and selfless are attributed as female, rather than male, characteristics (Dalley, 1996; Howard and Child Poverty Action Group (Great Britain), 2001). PoC is framed within a social justice lens and is concerned with injustices in the division of labour that caring practices create (Tronto, 1993). It relies on critical social theory to analyse the function of, and social status of, support activities for society, such as caring and *"…reflects on power relations and scrutinizes privilege that assigns performance of caring activities to people from lower status and income groups*" (Conradi, 2020, p. 2). This framing of caring came across in some participant accounts where they reflected on and challenged the unfairness of a system that placed the burden of care giving more on them than the state.

The effect of these responsibilising discourses is that they shift responsibility away from the LA and society more broadly, for the adverse effects of caring, and are silent to the disproportionate effects of, for example, gender and socio-economic status, or what Bacchi (1999) refers to as 'subjugated knowledges'. The problem of caring is not viewed as a collective or governmental problem, and it is not viewed as a problem for society beyond the landscape and language of health and social care. By fixing the problem of caring in the policy landscape of care and support legislation, is saying that it is not a problem for other parts of society. It silences the potential responsibility of other arms of the welfare state (education and social security systems). But it also silences the role and responsibility of other arms such as employment practices that support carers, or human rights law that give citizens basic rights and freedoms to, for example, a livelihood that many carers are often denied, or Equalities law that gave some characteristics protected status, such as pregnancy, but not caring.

The assumption that underpins the problem of caring, as a problem of the individual, is that people recognise and identify with the label carer. The guidance relies on people accepting that caring forms part of their identity particularly in relation to the prevention aspects of the guidance. The fact that so few carers have an assessment (demonstrated in the secondary analysis of SALT data) of their own need (less than 10% of the 5.4 million carers in England) which dropped to 7% in 2019/20, suggests a number of possibilities. One explanation could be the lack of identity with the construct.

If you do not identify with the construct, then it may be difficult to relate to services or facilities that are designed to help you, such as the Carers Centre model of delivery which is a UK building-based model of support that focuses exclusively on supporting carers. The effect of issues of self-identification have been debated in the literature for some time. Bittman *et al*, (2004); Montgomery and Rowe, (2007); Springer, (2007) argue that it takes time to recognise a shift from a primary relationship (partner, wife, husband, daughter and so on) to one of carer.

The policy intent that PBs give carers choice and control relies upon a particular understanding and socially-produced form of knowledge, that theories of personalisation are accepted as fact (Bacchi, 1999). It is this knowledge through which carers become governed and sets limits on how carers can come to understand themselves in relation to the role. Discourses of caring allows and limits the possibilities of understanding what can be said, by who, where, and when, and what is not said.

Theories of personalisation as facilitators of choice and control through assessment and support planning conversations, that put them front and centre at defining need and ways of meeting need, and PBs giving carers the ability to choose how public money is spent in ways that best meet need, introduces two competing ideologies. The idea of inclusive citizenship and active consumer (Fitzsimons and Fuller, 2002; Lymbery, 2012; Rabiee, 2012) play out in the Care Act guidance. Are carers being offered PBs as means towards their participation and inclusion in society (inclusive citizenship), or to make them more active consumers because they can ‘shop around’ for different products and services that will meet their needs? For participants in the phase three’s qualitative phase, it was neither. No participant expressed a sense that their PB meant that they were able to participate in economic and social life in the way that the Care Act suggested. Two participants disrupted normative accounts of PBs as facilitators of participation and inclusion and implied that the payment was a bribe, *"it's a bit of something really, just to keep you quiet [...] just a token thing to keep you quiet."* (extract 44).

WPR, as a mode of analysis, offered up a way to think about the interview data beyond what was said by participants to think about how it was possible for them to say what they did. It was possible to illustrate how ways in which participants represented their accounts of the impact of PB's spoke to a wider set of discourses that shaped how they talked about their role (Bacchi, 2016). For instance, one of the ways in which participants talked about their sense of duty and obligation spoke to a responsibilising discourse which placed the responsibility of care firmly with the family. Similarly, a number of participants positioned caring in the context of love, reciprocity, concern, and attentiveness which spoke to an Ethics of Care (EoC) theoretical explanation of what care means (Gilligan, 1993; Noddings, 1992).

This thesis proposes that dominant discourses (EoC) can leave participants feeling frustrated, guilty, and resentful at times for thinking about their own needs or feeling taken for granted by a government which assumes that their care will always be available or gives them very little in return for their contribution. By framing responsible carers as better carers because they accept the role with love, empathy, warmth, and responsibility, you, therefore, borrow the language of Foucault, construct the 'abnormal' or 'unnatural' carer who is irresponsible, who chooses not to care, and, therefore, is unloving, inattentive, or selfish. This makes it very difficult for participants to construct alternative views because they are going against normative assumptions and dominant discourses about what constitutes a successful caring relationship.

8.3 Do personal budgets improve carer subjective wellbeing?

8.3.1 Phase two: How the policy intentions played out

The quantitative findings suggest that PBs do not improve carer subjective wellbeing. This is evidenced by the regression analysis of 2018/19 SACE data which shows a statistically-significant association between PBs and carer wellbeing scores. PBs are associated with poorer wellbeing. Having a PB increases your wellbeing score by 0.078 point on the wellbeing scale (p=0.000); as lower scores are indicative of better wellbeing. This is corroborated by participant accounts from the analysis of semi-structured interview data. All participants gave accounts of PBs that made little, if any, material difference to their lives; in the main, because participants were not given any choice over how they could receive their PB or in how it could be spent. The idea that PBs (in the form of DPs) promote choice and control in terms of either active consumerism (shopping around with a DP) or inclusive citizenship (access to work, education and/or leisure) is not borne out by the findings from this thesis. This finding is supported in the literature, in particular by Jones *et al.* (2014), who found no positive correlation between service user PBs and carer wellbeing.

Findings from the secondary analysis of performance data also suggest that the policy intention, giving carers parity of esteem to assessment and support processes, has not led to an increase in the number of carers receiving assessment and support by CASSRs. SALT data show an overall decline in the numbers of carers being assessed and supported each year. This has dropped from 8% in 2014 to 7% in 2020. Given there are approximately 5.4 million carers in England (according to 2011 Census figures), very few carers are accessing help and support from LAs. Furthermore, the percentage of carers being assessed jointly with the person they care for dropped, from 41% in 2014/15 to 35% in 2015/16. No participants in the qualitative interviews were offered a joint assessment alongside the person they looked after. What is interesting from the national picture is the increased numbers of carers who receive DPs as a result of individual, rather than, joint assessments. In 2014/15 and 2015/16 10% of carers received a DP following an individual assessment compared with 3% of carers who had their needs jointly assessed during the same time period. This may indicate that it is more challenging to identify the needs of carers during joint assessments which is a finding supported in the literature (Seddon and Robinson, 2015).

Furthermore, when we look at the number of carers who receive assessment and support during the time period under investigation, we see that the vast majority receive advice and information as an outcome of their assessment. This represented 45% of carers assessed in 2014 which increased to 55.1% of carers in 2019/20. So, even though fewer carers were assessed by CASSRs in 2019/20, compared with earlier years, more carers received advice and information as an outcome of that assessment rather than a PB. Of the three modes of delivery to receive a PB, carers are more likely to take it as a DP (17% in 2014 and 21% in 2019), compared with the other two methods of part DP and commissioned support. This is corroborated in the qualitative findings where all participants who received a PB did so via a DP. This raises serious questions not just about the purpose and efficacy of PBs but of the assessment and support planning process as a whole. Given that a number of interviewees waited several months for an outcome of their carer’s assessment, it has to be asked what it is that people think they are waiting for, if the likelihood is that your outcome will be advice and information only.

The third policy intention, to give carers a greater sense of choice and control through outcomes-focused assessment and support-planning processes, is not occurring in practice from the evidence demonstrated in this thesis. Findings from the ASCOF outcome measures in phase two indicate no measurable improvements reported by survey respondents in either QoL scores, satisfaction with social services, and involvement in discussions about the care of the cared-for. In all three outcomes, measures for both QoL scores and satisfaction rates with social services reduced between 2014 and 2019. The same position was highlighted in the literature in the RCT carried out by Jones *et al.* (2014), who found no statistically-significant findings of improved social care outcomes for carers, which were used to measure participation (including employment), control over daily life, personal safety, and availability of care and support. Interviewees in this study backed up these findings. None of the 17 participants interviewed was asked during their carer's assessment what outcomes they would like to achieve in relation to broader life opportunities, such as work and/or education. One participant felt no choice but to give up a career she loved because it became impossible to balance the demands of care with employment.

8.4 The difference that PBs make to carers lives

8.4.1 Phase three: The lived effects of the policy intentions:

Responsibilising families to provide care is evidenced in findings from the analysis of semi-structured, qualitative interview data. Participants talked about the sense of duty and obligation they felt in relation to their caring role, and this was often characterised in relation to marriage vows, love, and reciprocity. Feeling responsible for the provision of care often meant that participants felt guilt for thinking about their own needs. This sense of responsibility cuts across all themes in the findings from feelings of guilt at leaving the person they cared for, to be looked after by paid carers, to guilt about feeling unable to cope with caring, or wishing to have time away, or returning to work. Bacchi (1999) describes this as a subjectification effect of discourse. Discourses produce practices (social work as a knowledge practice), and practices produce particular kinds of subjects. Carers occupy subject positions that render them 'responsible' carers. There is no other subject position to occupy because the dominant policy, and academic discourses, reinforce the role of, and responsibility for, the family to provide care.

Being categorized as a carer brings about a series of discursive practices that produce carers of a particular kind. A practice is where *"what is said and what is done [...] meet and interconnect"* (Foucault and Rabinow, 1984, p. 83) Carers' assessment and support plans become knowledge practices which establish who can receive a PB, and who cannot, through normative constructions of eligibility and wellbeing. The effects produced for some participants in the study was a lack of knowledge over whether they had been assessed, resulting in confusion as to whether or not they qualified for a PB and/or how a PB could be spent in a way that made life easier for them. Slasberg and Beresford (2016) refer to this as the 'de-personalising' effect brought about as a result of the gap between needs and resources. They suggest, that need is defined by the availability of resources rather than being defined by the outcomes the carer hopes to achieve, in spite of the claims made by the Act's guidance that *"the concept of meeting needs recognizes that everyone's needs are different and personal to them" (The Care Act, 2014 section 1, 1.10).* This position is supported by the narrative synthesis of the literature which found that decisions about services and support were often driven by bureaucratic mechanisms, such as assessment forms that were not able to capture the temporal and relational nature of the caring role (Seddon and Robinson, 2015).

Themes in the qualitative findings speak to some of the tensions created in caring roles, where some participants expressed a conflict between a commitment to caring where they are viewed, and view themselves, as primarily the responsible caregiver against the challenges of a social and political context in which formal support is limited. This context of caregiving against a backdrop where adequate support is unavailable to either carer or cared-for, cannot be divorced from individual accounts which construct emotions of guilt, isolation, despondency, and resignation. The relational aspects of carer and formal services is supported in the literature (Jones *et al.*, 2014; Larkin and Mitchell, 2015; Rand and Malley, 2014; Woolham *et al.*, 2018).

Assessment and support planning as a discursive practice problematizes caring as an individual issue that can be solved with a DP. The solution, therefore, is constructed as something that can improve a carer's life and enable them to balance caring with other responsibilities, such as employment and education. This position assumes that DPs can have the desired effect and are the only effective way in which carers are not disadvantaged by their roles. The political consequence which follows, is that carers lives are constructed purely in relation to their caring identities. Their needs are confined to care and support legislative frameworks, such as the Care Act, and public bodies (LAs) are given sole discretion and duty to implement the guidance produced by the Care Act (2014).

However, what can be seen in the data is the limited effect that care and support statutes like the Care Act can have when they categorize people solely in relation to their caring roles. The effect being that assessments and support plans do not consider people's identities as partners, employees, parents, siblings and so on, and, therefore, the relational effects of caring are ignored because they are constituted as a transactional relationship between carer and the LA and the PB process. Participant accounts speak to the limited effect of DPs being spent on replacement care for short-term, time-limited periods.

The blindness to relationality is played out in the data where participants orient their accounts of DPs in the context of a wider political process and normative constructs, which position and reinforce care as the responsibility and duty of family first and foremost.

Theme one identified in the interview data analysis speaks to the responsibilising and normalising effects of dominant sets of discourses both academic and political, where an ethics of care (EoC) theoretical framework occupies a position of hegemony (Conradi, 2019). Characterised by normative constructs of duty, love, responsibility, reciprocity, attentiveness, and empathy, participants come to understand the care that they give in this context. These normative claims, that families provide better care and those that accept responsibility for the provision of care, are, therefore, more loving and dutiful, have purchase both within policy, like the Care Act and academic discourses (Gilligan, 1982). However, four participant accounts disrupt and contradict the dominant discourse and locate the care they provide in a political context; identifying that care giving can be constituted as an activity that is socially unjust. This implies that some participants may frame themselves as right holders, people who have civil, political, and social rights and not just rights in terms of their caring identity. Lack of recognition from the state leads to frustration and resentment for four participants in the study.

Contradictory accounts show up in the thematic analysis of interview data, where participant accounts illustrate how the contradictory policy discourses impact on how carers come to understand their roles and what is possible for them to say and do. Participants often expressed contradictory emotional responses of guilt and resentment at thinking about their own individual needs and lost livelihood, careers, and sense of identity ran alongside feelings of love, duty, and obligation towards the person they care for.

To answer the central question about the extent to which PBs can promote the wellbeing of carers is also about answering a broader question about what wellbeing is attempting to do within the Care Act (2014), which is about promoting choice and control. The guidance makes clear that PBs not only improve wellbeing, but they also give people a greater degree of choice, because PBs allow people to choose how their needs are met. They have more control because they are front and centre of conversations about the way in which their needs are defined during assessment and in support planning conversations, about the best ways in which to meet those needs.

What this thesis has found, through all phases of the research, is that the concept of choice and control is a misnomer. The Care Act (2014) reflects a responsibilising agenda, and this thesis argues that the term carer has become a politically constructed concept for policy ends: to reduce the role of the government in the provision of care, and, therefore, reduce the cost of caring. For participants in the study, the idea that they have a sense of choice, agency, and control either in relation to how they receive a PB (either as DP, part DP or managed service), or how it is spent, is not borne out by their experience. All but two participants were told they had to spend their PBs on replacement care and only one participant was given a choice of the method of administration of her PB.

Choice and control for carers in this study was mediated through their individual circumstances and the relationships they had with the person they looked after, how effectively the cared-for person’s needs were being met by LAs and providers of care, and the extent to which carers felt valued for their contribution and value to society. This position is supported in the empirical literature.

Participants who took part in this study did not conceive of their wellbeing as an essential state, nor one that could be promoted through a one-off PB. For interviewees, their wellbeing (and how they felt about their caring role) was shaped by a range of complex factors that interplayed with each other at different times during the caring journey. For many interviewees their sense of wellbeing was inextricably linked with the wellbeing of the person they cared for. This corroborates the genealogical analysis of wellbeing, which showed that it is problematic to conceive of wellbeing as an objectively measurable state, because this misses the largely subjective knowledge of what wellbeing is. This was similarly supported by the narrative synthesis of the literature, which proposed that choice was mediated by the nature of the relationship with the cared-for and the availability of social care (Arskey and Glendinning, 2007).

The availability and affordability of services and support to the adult with care needs had a significant impact on interviewees' ability to balance their caring responsibilities and their own lives. Their sense of choice and control is mediated through many other factors that are often beyond their control, such as when the replacement carer will, or will not, arrive, how long they can stay for, and whether or not the LA will pay for the care, or whether the cared-for will accept outside help. For participants in the study, the way in which PBs were provided meant that many were unable to conceive of a career of their own, because the budget was too small to fund the care needed to be able to safely leave the adults while they worked.

The idea that the PBs process facilitates or gives people control is not an account that is reflected in the qualitative findings, and it conflicts with the concept of relationality that is evidenced in the qualitative data.

The concept that PBs promote choice and control is illusory both in terms of the qualitative and quantitative analyses. What PBs actually do is shift responsibility away from the State onto families, which, in effect, saves the LA a significant amount of money. As one participant put it *“it (DP) buys your silence”.* It’s a small pot of money to keep you providing the heavy end expensive care, so the LA doesn’t have to.

8.5 Summary

The central thesis of these findings, is, that for participants to be able to participate in economic and social life, and to feel included in society, it is important to recognise that caring is not simply about the care that one person provides for another, as a unidirectional experience, or, that participation can be ‘fixed’ by the provision of a PB, caring is both an ethical and political process that extends beyond the micro level interaction between people in families. If participation of carers in society is considered to be successful, caring, or, socially, just caring, then that cannot be achieved by a PB alone. To suggest that a one-off payment delivered by a LA to people with caring responsibilities can facilitate their involvement in all aspects of life, such as employment, education, and leisure does not consider that caregiving is as much a political, as it is a moral, endeavour, and, therefore, the ability of people to have their own lives whilst caring cannot be delivered by one arm of the welfare state alone.

Participation and inclusion of carers in society needs to be reconceptualized as both a relational and political process which bridges what are often characterized as two competing theories of care, ethics of care (EoC and PoC) (Conradi, 2020).

Relationality illustrates how the relationships carers have with professionals, providers of care, and society at large shapes ways in which they frame caregiving and the accounts they offer about the impact that PBs have on their lives. It is not simply a question of relationality between carer and cared-for (as an EoC would advocate), but carer, and provider, and government. Participant responses in the study highlight the complementarity that exists between these two theories, that explain what successful caregiving looks like that takes account of the potential exclusionary aspects of caring. This is supported in the literature by Tronto (2017) who calls for a bridging between EoC and PoC calling for an ‘ethico-political’ strand.

8.6 Conclusions

It is clear from the evidence presented in this thesis that the delivery of adult social care, without the 5.4 million carers in England, is simply not possible. Carers are an essential public service in delivering positive outcomes for adults with disabilities to use the language of the Care Act (2014).

The complexity of personalisation has been shown not to work for carers in the same way that it does for disabled adults. The idea that PBs can promote a carer’s participation and inclusion in economic and social life is unrealistic, given the evidence presented in this thesis.

What this thesis has shown, is, that a different body of knowledge is required to understand how personalisation can work for carers, if the true goal really is ensuring their rights to participation and inclusion in society in the same manner that non-carers enjoy. If that is the true intention of PBs then this thesis provides evidence of the nature of changes that are required to achieve this policy solution. Yet, the WPR analysis clearly points to the responsibilising effect of PBs as a policy solution to the problem of caring, which implies that the policy intention of PBs is to increase the role of the family in the provision of care. The construction of the term carer, now located in section 10 (3) Care Act (2014) (and contextualised in the Statutory Guidance) , can be seen as a politically- constructed term in order to achieve ideological ends to reduce the role and responsibility of government in the provision of care.

This thesis aims to build on the small body of evidence that is developing to understand the impact of the Care Act (2014) on carers' lives. Very few studies focus, exclusively, on the needs of carers, and this study has aimed to fill that gap, and to develop knowledge in this important area of practice. If personalisation is destined to stay and be mainstreamed, then more needs to be done to protect carers from the effect of caring on all aspects of their wellbeing.

Personalisation, as a policy programme, for carers with a fixed content where PBs deliver outcomes, does not work, the evidence presented in this thesis corroborates this assertion. It is not delivering a step change in the types or ways of providing support to carers that existed before the Care Act (2014), because the way in which it is implemented for participants in this thesis meant that they had no choice, whatsoever. The national evidence base corroborates this finding, from the perspective that PBs are not being taken as DPs in the way the Act intended. The vast majority of carers receive advice and information following a carers assessment, which begs the question: what is the purpose of an assessment? Personalisation has become more of a story, or way of thinking, about adult social care support rather than a way to actually deliver it.

The thesis identifies those areas where further research is required, to inform practice and issues that local and national policy actors need to consider, in relation to service design as knowledge grows on the effect that PBs are, or are not, making to carers' lives.

In terms of policy, change is needed on three levels: 1) Micro level – individual level assessment and support practices 2) Meso – organisational level change in relation to how

PBs are implemented, and eligibility criteria interpreted; and, 3) Macro – governmental level change that re-establishes a relationship between carers and government that acknowledges the impacts of caring from an exclusionary framework, giving light to political theories of care that recognise the disproportionate effects of caring on some groups more than others. This would lead to a more differentiate social policy response, where carers on lower incomes would be able to access greater financial support, and greater recognition of the gendered nature of care.

At the individual and organisational level, it is not just about procedural change in assessment technique, such as adjustment to assessment forms that fully embrace the broader needs of carers beyond simply respite care, but cultural and structural change in the ways in which society sees and values carers. It can no longer be viewed within the lens of care and support. There needs to be discussion, debate, and consideration of caring from an equalities and human-rights perspective that gives light to political theories of care. Cultural change refers to the change in mind-set of practitioners who still think in service delivery mode and assume a family's willingness and ability to provide care. Practical considerations, too, of shifting away from separate income streams where carers budgets are held separately from service-user budgets.

Family budgets, in adult social care, could be a positive way forward in removing some of the barriers and challenges that exist with the ways in which carers are supported under the Care Act (2004). Increased choice for service users should not be at the expense of increased stress for carers.

Appendix one: Purpose and parameters of the review

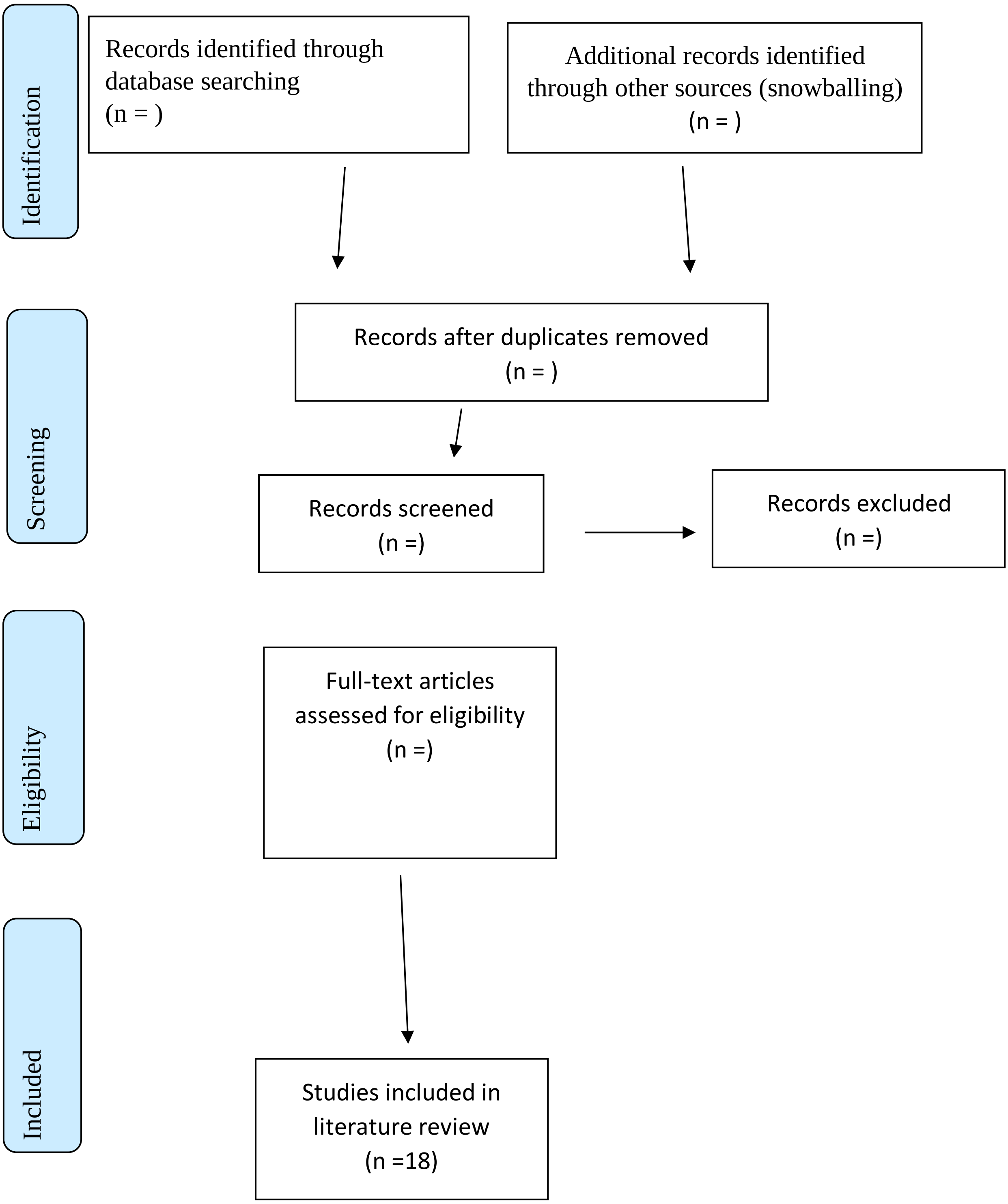
Table 16. Purpose and parameters of the review

Topic	• Exploring the effectiveness of the Care Act (2014) in promoting the wellbeing of carers through the use of PBs
Scope	•Examining the policy intention behind PBs as a policy solution to the problem of caring •Identifying if PBs have impacted upon reported levels of carer subjective wellbeing •Adult carer population in England only
Background	•Limited knowledge on the effects of carer specific PBs on carers lives. What does exist is limited to grey literature only. •Empirical evidence suggests that socio-demongraphic variables impact wellbeing and abiliyt to participate in economic and social life more than caring.
Purpose	•Testing the Care Act's claim that PBs will facilitate a carers invlovment and particpation in society, such as access to employment, education and leisure.
Aim	•The study aims to explore the social inclusion and particpaiton that carers experience by assessing the impact of the Care Act (2014) on the social experience of caring. Specifically this is acheived by assessing th effectiveness of the Care Act's claim that a carers wellbeing can be promoted by the administration of a PB.

Appendix two: Using STARLITE to assess the quality of my search

Sampling strategy	*Comprehensive*
Type of studies	*Any kind of qualitative or quantitative primary peer-reviewed research and systematic reviews that identifies factors that contribute to the social exclusion and marginalisation of carers.*
Approaches	*Electronic database search, Subject search; snowballing; internet searching (organisational research).*
Range of years (start date – end date)	*Applied a start date of 1990 to reflect the date at which the term carer first emerged in public discourse. No end date limiter.*
Limits	*English; human; adult over 18 years (Care Act applies to adults only), peer-reviewed, full text*
Inclusions and exclusions	*Exclusion: Adults caring for children and children caring for adults. Studies that do not relate to PBs or their impacts on carers participation and inclusion in society. Papers that relate to PBs and their delivery outside of the UK.* *Inclusion: Any paper that meets the aim and focus of the study. For example, papers that identify, measure, or evaluate the impact of PBs on a carers experience of life (wellbeing). Papers that discuss the effectiveness of the Care Act (2014) in improving carer wellbeing. Papers that discuss factors that affect the participation and inclusion of carers in society. Papers that discuss/evaluate the impact of PBs on carers lives.*
Terms used	*"caregiver*" or "informal carer*" or "informal caring" or "caring" or "carer" AND "carer stress" or "carer burden" or "carer impact" AND "personal budget" or "direct payment" or "personalisation" AND "inclusion" or "include" or "participation" or "involve*" AND "wellbeing" or "well-being" or "social" or "economic" AND "Care Act 2014" or "Care Act"*
Electronic sources	*CINAHL complete, Medline, EJournals, PsychARTICLES, PsychINFO, Community Care Inform, Social Care Online, Sage Journals, Jiscmail (carer research directory), RIPFA (research in practice for adults), JTSTOR, Google Scholar, ASSIA (Applied Social Sciences Index and Abstracts), Social Services Abstracts Scopus, Web of Science, Science Direct, Proquest dissertations, Google Scholar*

Appendix three: Prisma Flow Diagram



Appendix four: – Interview topic guide

Objectives:

- To explore what participation and inclusion means to participants with caring responsibilities
- To understand the impact and outcome of personal budgets on carers' ability to participate in economic, social, and cultural life

Themes to be explored:

Involvement in the assessment (carer) and support planning process

- How carers assessment introduced
- How outcomes and need identified during assessment
- Choice, preferences and wishes as part of the assessment process
- How decisions made about expenditure of Personal budget (PB)

Impact and outcome of personal budgets (PB)

- Types of changes occurring as result of PB (prompts: level and type of support/care provided, return to employment/education/opportunity for leisure/relationships/improved health and wellbeing)
- Identifiable patterns in these changes, e.g., more carers reporting improved health or time for leisure rather than ability to enter the labour market.
- Identifiable patterns in these changes for particular types of carers e.g., by age, gender, ethnicity

Carer expectations of impact of PB

- Carer perception on purpose and value of PB
- Type of information received by services on purpose, nature, and benefit of PB
- Reflections on difference made
- Carer perception on purpose and value of carers assessment process

Appendix five: Copy of do file used to create commands

Version 16.1

```
Clear all
Set memory off
Capture log close

*import 2018_19 SACE Data set*
Import excel “C\Users\User\Documents\Kathryn Chard work\PhD proposal\PhD chapters\chapter five findings and analysis\Data sets\Survey of adult carers data\SACE 2018-19\pss_sace_2018_19_data.xlsx”, sheet(“pss_sace_2018_19data”) firstrow

*examine variables of interest*
Des SupportToCarer
Sum SupportToCarer
Inspect SupportToCarer
Tab SupportToCarer
Codebook SupportToCarer

Des gender
Sum gender
Inspect gender
Tab gender
Codebook gender

Des agregrp
Sum agregrp
Inspect agegrp
Tab agegrp
Codebook agegrp

Des ethgrp
Sum ethgrp
```

```
Inspect ethgrp
Tab ethgrp
Codebook ethgrp


Des Q7
Sum Q7
Inspect Q7
Tab Q7
Codebook Q7

Des Q8
Sum Q8
Inspect Q8
Tab Q8
Codebook Q8

Des Q9
Sum Q9
Inspect Q9
Tab Q9
Codebook Q9

Des Q10
Sum Q10
Inspect Q10
Tab Q10
Codebook Q10

Des Q11
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Sum Q11
Inspect Q11
Tab Q11
Codebook Q11

Des Q12
Sum Q12
Inspect Q12
Tab Q12
Codebook Q12

*remove value 99 ‘record suppressed’ as not useful to the analysis and recode*/ * as missing (.) this only applies to gender agegrp and ethgrp*
Mvdecode gender, mv(99+=.)
Mvdecode agregrp, mv(99=.)
Mvdecode ethgrp, mv(99=.)

*check the recoding has worked*
Tab gender
Tab agregrp
Tab ethgrp

*remove value 3 ‘other’ from gender as there is no way of knowing what gender identify thie refers to and it accounts for four observations only*
Drop if SupportToCarer ==.
Drop if gender ==.
Drop if agregrp ==.
Drop if ethgrp ==.
Drop if Q7 ==.
Drop if Q8 ==.
```

```
Drop if Q9 ==.
Drop if Q10 ==.
Drop if Q11 ==.
Drop if Q12 ==.

*check missing values have been removed*
Inspect SupportToCarer
Inspect gender
Inspect agegrp
Inspect ethgrp
Inspect Q7
Inspect Q8
Inspect Q9
Inspect Q10
Inspect Q11
Inspect Q12

*Recode gender into binary form so male = 0 and female = 1*
Recode gender (1=0) (2=1)
Label define gender 0 “male” 1 “female”
Label values gender gender
Tab gender

*recode SupportToCarer so that values 1-3 become PB and 4-6 No PB, apply value label to SupportToCarer*
Recode SupportToCarer (4 5 6=0) (1 2 3=1)
Label define SupportToCarer 0 “No PB” 1 “PB”
Label values SupportToCarer SupportToCarer
Tab SupportToCarer
```

```
*apply value labels to agegrp 0=18 and 1=65≥*
Recode agegrp (1=0) (2=1)
Label define agegrp 0 “18-64” 1 “65≥”
Label values agegrp agegrp
Tab agegrp

*apply value labels to ethgrp but first remove value 3 ‘refused’*
Mvdecode ethgrp, mv(3=.)
Drop if ethgrp ==.
Recode ethgrp (2=0)
Label define ethgrp 0 “BAME” 1 “white”
Label values ethgrp ethgrp
Tab ethgrp

*recode Q7-Q12 to reflect the question’s topic and apply value labels*
Rename (Q7 Q8 Q9 Q10 Q11 Q12)(timeval controldl selfcare persafe socialcon supptoca)
.label variable timeval “time doing things I value”
.label variable controldl “control of daily life”
.label variable selfcare “looking after yourself”
.label variable persafe “personal safety”
.label variable socialcon “social contact”
.lable variable supptoca “support to carer”
Label define timeval 1 “spend tim as I want” 2 “some time as I want but not enough” 3 “no time to spend on me”
Label values timeval timeval
Tab timeval
Label define controldl 1 “have as much control as I want” 2 “some control but not enough” 3 “no control over my life”
Label values controldl controldl
Tab controldl
```

```
Label define selfcare 1 “I have time to look after myself” 2 “some time to look after myself but not enough” 3 “no time to look after myself”

Label define persafe 1 “I have no worries about my safety” 2 “I have some worries about my safety” 3 “I am extremely worried about my safety”

Label define socialcon 1 “I have as much social contact as I want” 2 “I have some social contact but not enough 3 “I have little social contact and feel isloated”

Label define supptoca 1 “I have encouragement and support” 2 “I have some encouragement and support but not enough” 3 “I have no encouragement and support”


*create a wellbeing variable as a continous outcome varialbe turn this into a summated scale using Q7-12 which closely align with wellbeing indiciators*

Corr timeval controldl selfcare persafe socialcon supptoca

alpha timeval controldl selfcare persafe socialcon supptoca

alpha timeval controldl selfcare persafe socialcon supptoca, detail item

egen wellbeing = rowmean (timeval controldl selfcare persafe socialcon supptoca)

codebook wellbeing

label variable wellbeing “wellbeing”

label define wellbeing 1 “I have as much wellbeing as I want” 2 “I have some wellbeing but not enough” 3 “I have no wellbeing”

label values wellbeing wellbeing

tab wellbeing


*Descriptive stats on the newly created outcome variable and predictor variables*

Histogram wellbeing

Tab wellbeing SupportToCarer

Tab wellbeing gender

Tab wellbeing agegrp

Tab wellbeing ethgrp

Tab wellbeing SupportToCarer

Tab wellbeing gender

Tab wellbeing agegrp

Tab wellbeing ethgrp
```

```
*show preliminary associates between the dep and predictor variables*
Reg wellbeing SupportToCarer
Reg wellbeing SupporToCare gender
Reg wellbeing SupportToCarer gender agegrp
Reg wellbeing SupportToCarer gender agegrp ethgrp
Test ethgrp
Test agegrp
Test gender
Test SupportToCarer
Corr wellbeing SupportToCarer gender agegrp ethg
```

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