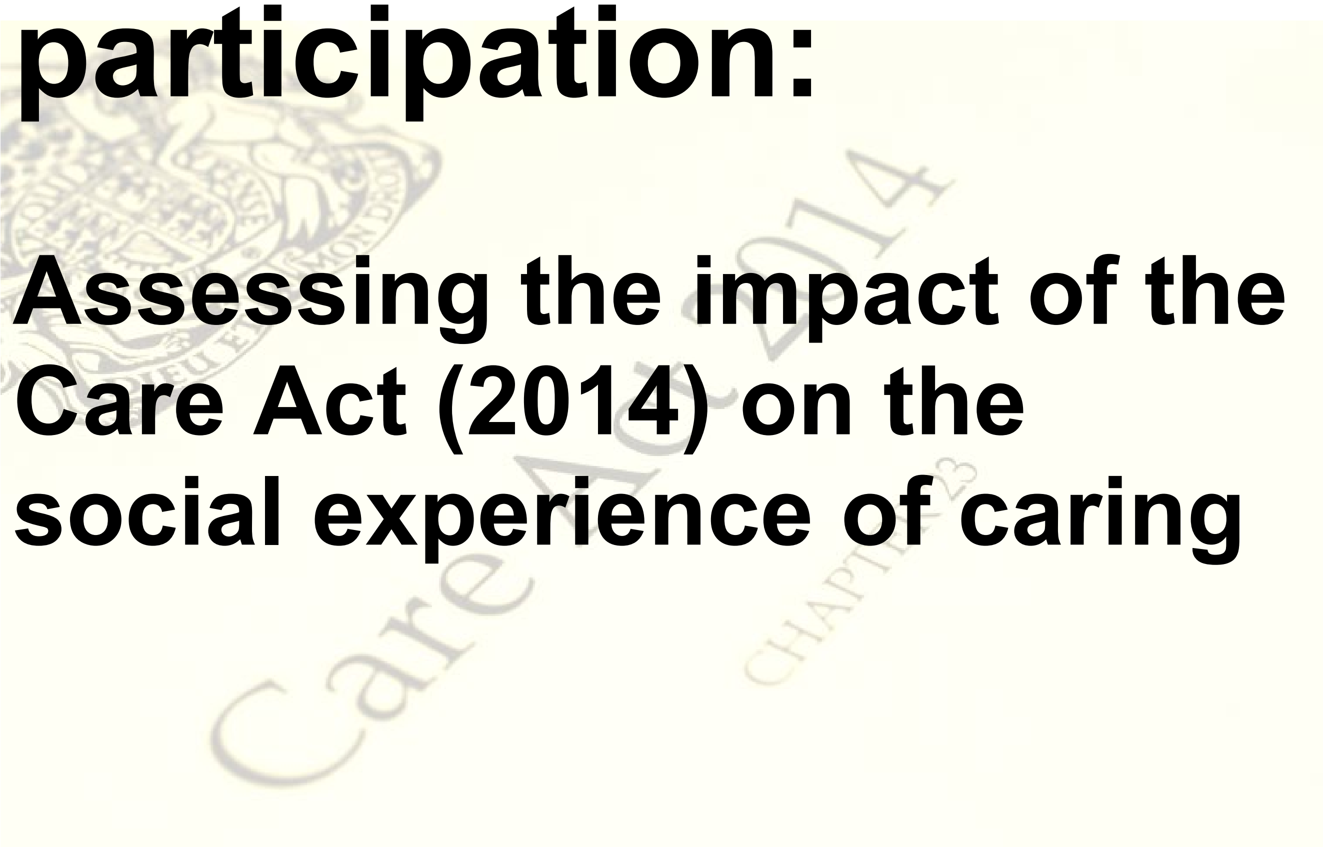
University of Essex

Executive Summary of PhD Research Findings

Exploring social inclusion and participation:



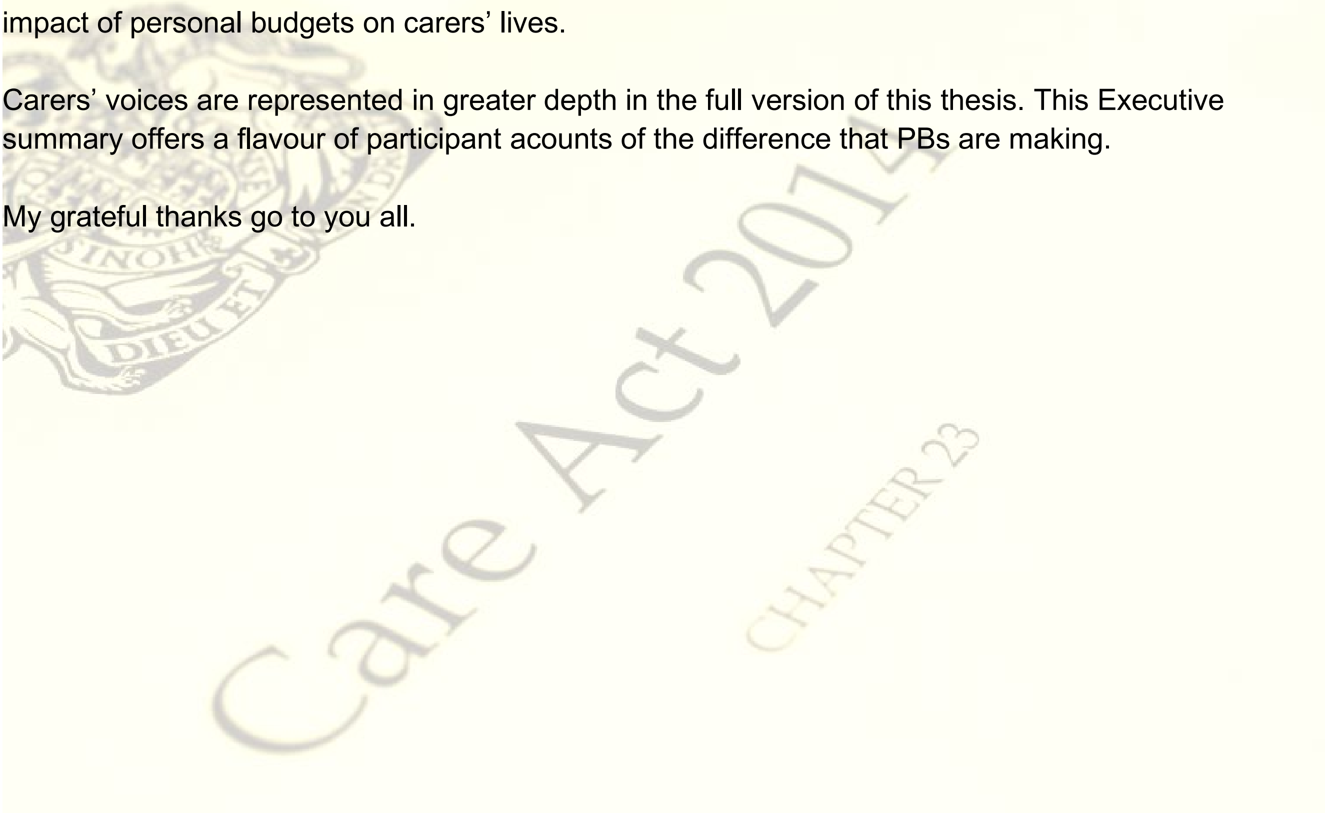
Assessing the impact of the Care Act (2014) on the social experience of caring

Acknowledgments

This Executive summary would not be possible without the contribtuion of the people with caring resonsibilities who so generously shared their time and their experiences of receving a personal budget (PB) with me. Their insights and knoweldge were fundamental in shining a light on the impact that PBs were having on their ability to balance caring with their own lives. The lived experience of people on the receiving end of PBs tells the important narrative behind the statistical analysis of the impact of personal budgets on carers' lives.

Carers' voices are represented in greater depth in the full version of this thesis. This Executive summary offers a flavour of participant acounts of the difference that PBs are making.

My grateful thanks go to you all.



Authors: Dr Kathryn Chard
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Contents

1 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.

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. 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.

Yet a weight of evidence exists that tells us just how much caring can impact upon a person's ability to balance their own life alongside a caring responsibility. Carers' rights legislation has evolved because of the acknowledgment of the disproportionate effects that caring can have on all aspects of a person's health and wellbeing compared to the population without caring responsibilities.

This research came about because of a personal experience of caring and professional practice as a Social Worker and Carers Lead Officer with commissioning responsibilities for carers services in two Local Authorities in England. I witnessed and experienced first-hand the challenges of providing care in the context of a health and social care system that relied and still relies heavily upon family, friends and neighbours for the provision of care and support. I wanted to explore the extent to which carer personal budgets were addressing the needs of carers and supporting their participation and inclusion in economic and social life.

2 Abstract

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 research sought to explore this knowledge gap using a mixed-methods design built around three phases.

Each phase was carried out as a separate study as follows:
Phase one: Examined the intentions behind PBs as a solution to the problem of caring: A post-structural policy analysis of Care Act (2014) statutory guidance using: 'What's the Problem Represented to be?' (WPR) method.

Phase two: Identified if the policy intentions led to improvements in carer wellbeing: A quantitative secondary descriptive analysis of national performance data and inferential analysis of carer specific survey data.

Phase three: Explored the lived effects of the policy intentions: A thematic analysis of interview data with 17 carers.

Findings suggest that the Care Act (2014) statutory 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 in the study.

This research recommends that care giving needs to be better understood as both an ethical and political process that extends beyond the micro level interaction between people in families. Social inclusion and participation of carers in society cannot be achieved by the actions of Councils with Adult Social Care Responsibility (CASSR) alone. A whole system, whole family approach which recognises that carer identification and support is everyone's responsibility is one way forward. Whole family or integrated PBs may take us one step towards this aspiration.

2.1 Background and context

The aim of the research was to assess the extent which personal budgets (PBs), and their framing as a policy solution to the problem of caring, in the Care Act (2014), could promote the wellbeing of people with caring responsibilities (referred to as carers in this paper) in England.

The purpose of the assessment was to understand whether current English legal provisions were able to stand up to the policy rhetoric 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"*.[1]

In England, the Care Act (2014) was announced as a major reform of adult social care law.[2] 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"*.[3] A forthright claim, it committed the government to transforming health and social care through personalisation and community-based support.[4] 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.[1] 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

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[1] Care Act 2024, c.23 available at: https://www.legislation.gov.uk/ukpga/2014/23/data.xht?wrap=true

[2] Whittington, C. (2016) 'The Promised Liberation of Adult Social Work under England's 2014 Care Act: Genuine Prospect or False Prospectus?', *The British Journal of Social Work,* 46(7), pp. 1942-1961

[3] Department of Health (2014) *Care Bill becomes Care Act.* Available at: https://www.gov.uk/government/speeches/care-bill-becomes-care-act-2014

[4] Feldon, P. (2017) *The Social Worker's Guide TO THE CARE ACT 2014.* St. Albans: Critical Publishing.

systems to support carers.[5] [6] [2] 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.

2.1.1 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")"*. 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).

2.1.2 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.[7] [8]

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[5] Mitchell, W., Brooks, J. and Glendinning, C. (2014) 'Carers' Roles in Personal Budgets: Tensions and Dilemmas in Front Line Practice', *The British Journal of Social Work,* 45(5), pp. 1433-1450

[6] Seddon, D. and Robinson, C. (2015) 'Carer assessment: continuing tensions and dilemmas for social care practice', *Health Soc Care Community,* 23(1), pp. 14-22

[7] Slasberg, C. and Beresford, P. (2016) 'The eligibility question – the real source of depersonalisation?', *Disability & Society,* 31(7), pp. 969-973.

[8] Morris, J. (1999) The Meaning of Independent Living in the 3rd Millennium. *In:* Research, T.o.t.d.a.t.U.o.G.C.f.D. (ed.). The University of Glasgow

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.[9] [10] 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[11] [12] and 2000s. [13] [14] There is a substantive literature reporting that carers are more likely to experience problems with

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[9] Brostoff, P. M. (1989) 'Book Reviews : Policy Is Personal: Sex, Gender and Informal Care. By Clare Ungerson. London: Tavistock Publications, 1987, 166 pp., $45.00, cloth, $19.95, paperback', *Affilia,* 4(3), pp. 91-93.

[10] Heaton, J. (1999) 'The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care', *Sociology of Health & Illness,* 21(6), pp. 759-777.

[11] Dalley, G. (1996) *Ideologies of caring : rethinking community and collectivism. Women in society* 2nd edn. Basingstoke: Macmillan in Association with the Centre for Policy on Ageing.

[12] Twigg, J., Great Britain. Department of Health. and University of York. Social Policy Research Unit. (1992) *Carers : research and practice.* London: H.M.S.O.

[13] Barnes, M. (2006) *Caring and social justice.* Basingstoke: Palgrave Macmillan.

[14] Howard, M. and Child Poverty Action Group (Great Britain) (2001) *Paying the price : carers, poverty and social exclusion. Poverty publication* London: Child Poverty Action Group.

their wellbeing and health compared to the non-caring population. [15] [16] [17] [18] [19] [20] [21] [22] [23] [24] [25] [26] [27] [28] [29]

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. 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.[30] [31] [32] [33] [34]

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[15] Borren, I., Tambs, K., Gustavson, K. and Sundet, J. M. (2014) 'Psychological distress in spouses of somatically Ill: longitudinal findings from The Nord-TrØndelag Health Study (HUNT)', *Health and Quality of Life Outcomes,* 12(1), pp. 139.

[16] Bucki, B., Spitz, E., Etienne, A.-M., Le Bihan, E. and Baumann, M. (2016) 'Health capability of family caregivers: how different factors interrelate and their respective contributions using a Bayesian approach', *BMC Public Health,* 16(1), pp. 364.

[17] Carmichael, F. and Ercolani, M. G. (2016) 'Unpaid caregiving and paid work over life-courses: Different pathways, diverging outcomes', *Soc Sci Med,* 156, pp. 1-11.

[18] Folbre, N. and Nelson, J. A. (2000) 'For Love or Money--Or Both?', *Journal of Economic Perspectives,* 14(4), pp. 123-140.

[19] Garlo, K., O'Leary, J. R., Van Ness, P. H. and Fried, T. R. (2010) 'Burden in caregivers of older adults with advanced illness', *J Am Geriatr Soc,* 58(12), pp. 2315-22.

[20] Greenwood, N. a. S., R.(2016) 'The oldest carers: A narrative review and synthesis of the experiences of carers aged over 75 years', 94, pp. 161-172, Available: Elsevier Ireland Ltd. DOI: 10.1016/j.maturitas.2016.10.001.

[21] Horner-Johnson, W., Dobbertin, K., Kulkarni-Rajasekhara, S., Beilstein-Wedel, E. and Andresen, E. M. (2015) 'Food Insecurity, Hunger, and Obesity Among Informal Caregivers', *Preventing chronic disease,* 12, pp. E170-E170.

[22] Irfan, B., Irfan, O., Ansari, A., Qidwai, W. and Nanji, K. (2017) 'Impact of Caregiving on Various Aspects of the Lives of Caregivers', *Cureus,* 9(5), pp. e1213.

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[24] Pivodic, L. V. D. B., L.; Pardon, K.; Miccinesi, G.; Alonso, T.V.; Boffin, N.; Donker, G.A.; Cancian, M.; Lopez-Maside, A.; Onwuteaka-Philipsen, B.D.; Deliens, L.; Zeger, D.G.;(2013) 'Burden on family carers and care-related financial strain at the end of life: A cross-national population-based study', 24, pp. 819-826. DOI: 10.1093/eurpub/cku026.

[25] Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M. and Haley, W. E. (2009) 'Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults', *Qual Life Res,* 18(6), pp. 679-88.

[26] Shahly, V., Chatterji, S., Gruber, M. J., Al-Hamzawi, A., Alonso, J., Andrade, L. H., Angermeyer, M. C., Bruffaerts, R., Bunting, B., Caldas-de-Almeida, J. M., de Girolamo, G., de Jonge, P., Florescu, S., Gureje, O., Haro, J. M., Hinkov, H. R., Hu, C., Karam, E. G., Lépine, J. P., Levinson, D., Medina-Mora, M. E., Posada-Villa, J., Sampson, N. A., Trivedi, J. K., Viana, M. C. and Kessler, R. C. (2013) 'Cross-national differences in the prevalence and correlates of burden among older family caregivers in the World Health Organization World Mental Health (WMH) Surveys', *Psychol Med,* 43(4), pp. 865-79.

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Slasberg, C. and Beresford, P. (2016) 'The eligibility question – the real source of depersonalisation?', *Disability & Society,* 31(7), pp. 969-973.

[28] Vasileiou, K., Barnett, J., Barreto, M., Vines, J., Atkinson, M., Lawson, S. and Wilson, M. (2017) 'Experiences of Loneliness Associated with Being an Informal Caregiver: A Qualitative Investigation', *Frontiers in Psychology,* 8(585).

[29] Verbakel, E., Tamlagsronning, S., Winstone, L., Fjaer, E. L. and Eikemo, T. A. (2017) 'Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health', *Eur J Public Health,* 27(suppl_1), pp. 90-95.

[30] Dittrich, R. 2013. Innovative use of Carers Direct Payments: Ideas from good practice *Social Care Evidence in Practice (SCEiP).* London: London School of Economics.

[31] Jones, K., Netten, A., Rabiee, P., Glendinning, C., Arksey, H. and Moran, N. (2014) 'Can individual budgets have an impact on carers and the caring role?', *Ageing and Society,* 34(1), pp. 157-175.

[32] Larkin, M. a. D., H. and 2011. Personalisation: what will the impacts be for carers?

[33] Moule, P., Pollard, K., Clarke, J., Fear, C., Lawson, B., Thompson, R. and Young, P. (2014) 'An integrated approach for individualised support: carers' views', *Journal of Integrated Care,* 22(5/6), pp. 253-262.

[34] Woolham, J., Steils, N., Daly, G. and Ritters, K. (2018) 'The impact of personal budgets on unpaid carers of older people', *Journal of Social Work,* 18(2), pp. 119-141.

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.[35] [36] 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.[37] 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.

The progression of this argument is that financial savings are seen as the governmental agenda for care and support legislative reforms 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.[38] 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 can 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

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[35] Clements, L. (2013) 'Does Your Carer Take Sugar? Carers and Human Rights', *Washington and Lee Journal of Civil Rights and Social Justice,* 19(2), pp. 398-431.

[36] West, K. (2013) 'The grip of personalization in adult social care: Between managerial domination and fantasy', *Critical Social Policy,* 33(4), pp. 638-657.

[37] Bartlett, J. (2009) *At Your Service: Navigating The Future Market in Health and Social Care.* London: Demos.

[38] Buckner, L. a. Y., S. (2015) *Valuing Carers 2015* [Report]: University of Leeds and University of Sheffield. Available at:file:///C:/Users/kathr/OneDrive/Documents/Kathryn%20Chard%20work/PhD%20proposal/EndNote%20library/cuk-valuing-carers-2015-web.pdf

policy intention behind PBs, as a solution to the problems that carers face, became a way of assessing that claim (phase one of the research).

Similarly, it is 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. 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 the research).

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 was the central question that the research sought to resolve and by examining the national evidence base in the form of carer- specific performance and survey data, this offered 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 had been (phase three of the research).

3 Introduction to the Research Design

The study was designed around three phases, each with its own research question and methodological approach. Each phase ran concurrently alongside the other. A mixed methods design was chosen because of the ontologically competing research questions which necessitated different design choices being made. This complimentary model of research is endorsed by Cairney (2013) who recommends this structural approach for mixed methods designs. [39]

- 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?

3.1. What are the policy intentions behind PBs for carers?

Phase one examined the 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 on 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? This method of analysis offered a discursive way to analyse the way in which policies construct problems in particular ways. The WPR approach (developed by Carol Bacchi in '90s) offers the researcher a set of analytical practices (in the form of a six-question model – see appendices two and three), that facilitates a way to question the way that caring is 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

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[39] Cairney, P. (2013) 'Standing on the Shoulders of Giants: How Do We Combine the Insights of Multiple Theories in Public Policy Studies?', *Policy Studies Journal,* 41(1), pp. 1-21.
UK, *The Care Act* (2014)Chapter 23).

policy solutions, which are referred to as problematizations. Bacchi's approach allows the questions to illustrate the presumptive nature of policy solutions, which 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. (see appendix two for a description and rationale for using this method of analysis).

3.2 Are the policy intentions realised in practice?

Phase two examined if the policy intentions were realised in practice. Were carer specific PBs improving carer wellbeing in the way that the Care Act (2014) conceived of wellbeing (to include participation in economic and social life)? This phase of the study aimed to test the following five hypotheses.

- Hypothesis 1 – Short- and Longer-Term returns (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.
- Hypothesis 2 - Carers will report increases in their Quality of Life (QoL) scores between 2012 and 2019.[40]
- 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.
- Hypothesis 5 - Having a PB promotes carer wellbeing (measured via constructed wellbeing outcome variable).

The impact of PBs were measured in this phase of the study 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 in 2020). 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 (including a PB).

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

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[40] 2012 is chosen as the start date for all ASCOF outcome measures as this represents the first Survey of Adult Carers in England (SACE) survey data collection period.

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. [41]

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 improved 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 (see appendix six for data sets used in this study and their corresponding hypotheses).

3.3. What are the lived effects of the policy intention?

Phase three 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

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[41] NHS Digital, 2020. Adult Social Care Data Hub – NHS Digital [https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/adult-social-care-data-hub] Accessed 14/03/2023

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 perspective. 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?

Participants were recruited from a carers charity in the East of England region, using a convenience sampling strategy. A total of 17 participants took part in semi-structured interviews. Interview data were analysed using Braun and Clarke (2014) six-stepped approach to thematic analysis. [42] The majority of interviewees were female (78% - n=14) and 22% male (n=3). Participant mean age was 63. Of the sample, 58.8% (10 out of 17) were spousal carers, co-resident with the person they cared for. Adult children caring for ageing parents comprised 17.6% (three out of 17) of the sample (two of whom lived with their parent). The remainder of participants (23.5% or 4 out of 17) were parent carers. Three out of the four parent carers were co-resident with their adult children and one was accommodated in a residential setting. 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. Interviews were held between June and December 2018.

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[42] Braun, V. and Clarke, V. (2014) 'What can "thematic analysis" offer health and wellbeing researchers?', *International Journal of Qualitative Studies on Health and Well-being,* 9(1), pp. 26 - 152.

4 Findings

4.1 Phase one: What were the policy intentions behind personal budgets as a solution to the problem of caring?

This section presents findings from the analysis of the way in which the statutory guidance represents caring as a particular sort of problem, which 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.[43]

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.

4.1.1 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)).

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[43] Department of Health (2014) Care and Support Statutory Guidance: Issued under the Care Act 2014, London: Department of Health.

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).

4.1.1.1 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.

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 (see chapter four of the full thesis). 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.

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. It highlights one of the challenges of rights based discourses. In that the rights of one person, may impact and/or diminish the right of another. This is particularly pertinent in a social care setting where the adult with care and support needs may wish to be cared for at home, yet this may come at a significant cost to a family carer.

4.1.1.2 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 (see chapter three, full thesis).

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.

4.1.2 Problematisations of eligibility determination

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 (see appendix three – carer eligibility table). The eligibility table 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 (appendix three), 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 (see chapter five, full thesis).

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.

4.1.3 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. The empirical evidence suggest that gender, income and social class are important determinants of carer health and wellbeing. Women and those caring in the lower income and social class groupings are not only more likely to become carers compared to men and those in higher income and social class categories. They are also more likely to be found in more intensive caring roles (caring for 20 hour per week or more) and caring for longer time periods over the course of the lives).[44] [45] [46]

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

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[44] Carmichael, F. and Ercolani, M. G. (2016) 'Unpaid caregiving and paid work over life-courses: Different pathways, diverging outcomes', *Soc Sci Med,* 156, pp. 1-11.

[45] Henz, U. (2006) 'Informal Caregiving at Working Age: Effects of Job Characteristics and Family Configuration', *Journal of Marriage and Family,* 68(2), pp. 411-429.

[46] Pierret, C. R. (2006) 'The Sandwich Generation: Women Caring for Parents and Children', *Monthly Labor Review,* 129(9), pp. 3-9.

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.[47] [48] [49] 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.

4.1.4 Summary of phase one findings

Carrying out a WPR analysis of the intentions behind PBs as solution to the problems that carers face 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.

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.

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[47] Gilligan, C. (1993) *In a Different VoicePsychological Theory and Women's Development.* Harvard University Press.

[48] Tronto, J. C. (1993) *Moral boundaries : a political argument for an ethic of care.* New York: Routledge.

[49] Ungerson, C. (1997) 'Social Politics and the Commodification of Care', *Social Politics: International Studies in Gender, State & Society,* 4(3), pp. 362-381.

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 appear to be more about a transaction than they are about a carer's participation and inclusion in economic, social, and cultural life.

4.2. Phase two: Were the policy intentions realised in practice?

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 indicate better wellbeing (see table two on page 31).

4.2.1 Hypothesis one – 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.

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. Hypothesis one is therefore rejected.

The number of carers assessed, dropped from 8% in 2014 to 7% in 2020 (see figure one below). 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. 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. [50]

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

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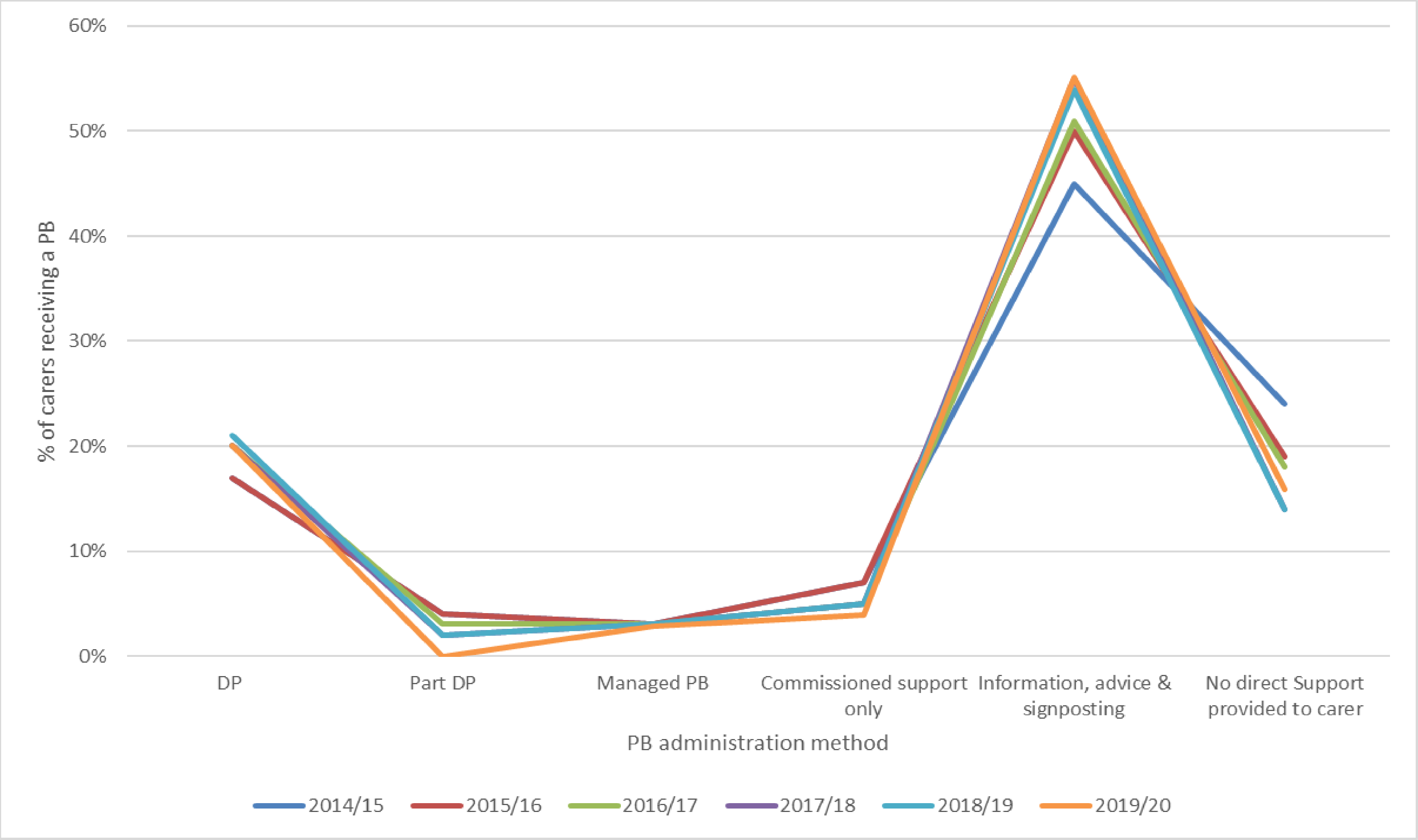
[50] Seddon, D. and Robinson, C. (2015) 'Carer assessment: continuing tensions and dilemmas for social care practice', *Health Soc Care Community,* 23(1), pp. 14-22.

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 raises questions not just about the purpose and efficacy of PBs but of the carer assessment and support planning process as a whole.

Figure 1 Number of carers receiving a PB by method of administration in England as a percentage - 2014 to 2020

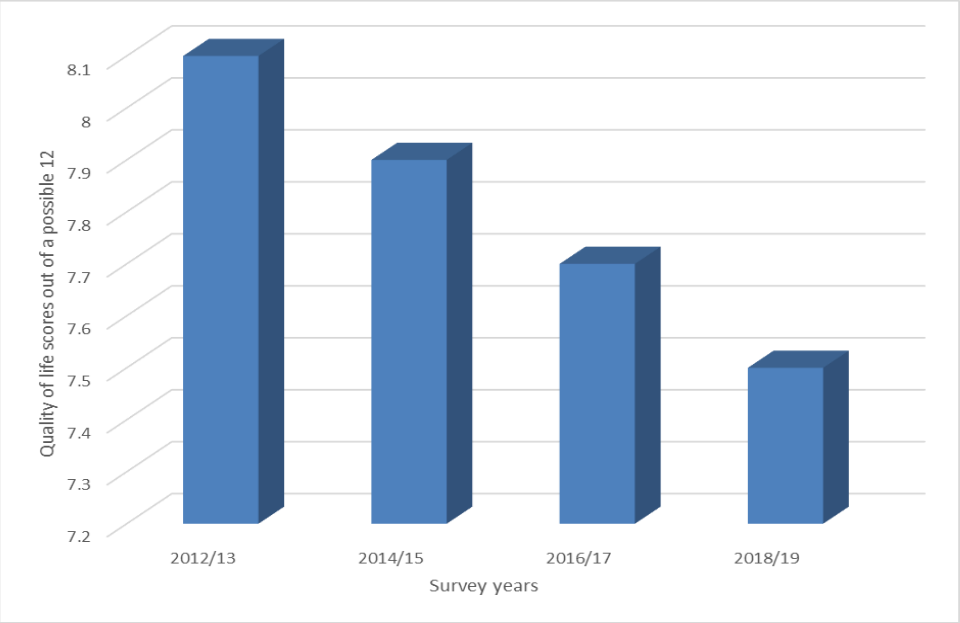


4.2.2 Hypothesis two – Carers will report increases in their QoL scores between 2012 and 2018

Findings from analysis of carer reported QoL scores show a steady decline over the time period under investigation. QoL scores reduced from 8.1 in 2012/13 to 7.5 in 2018/19 (see figure two below).

The quality of life score (QoL) score is a composite measure made up of six questions from the Survey of Adult Carers in England (SACE). Figure three on the next page shows satisfaction rates between 2012/13 and 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 QoL measures have steadily declined between 2012 and 2019, as lower scores represent a poorer 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.[51]

Figure 2 ASOF carer reported QoL scores - 2012 to 2019



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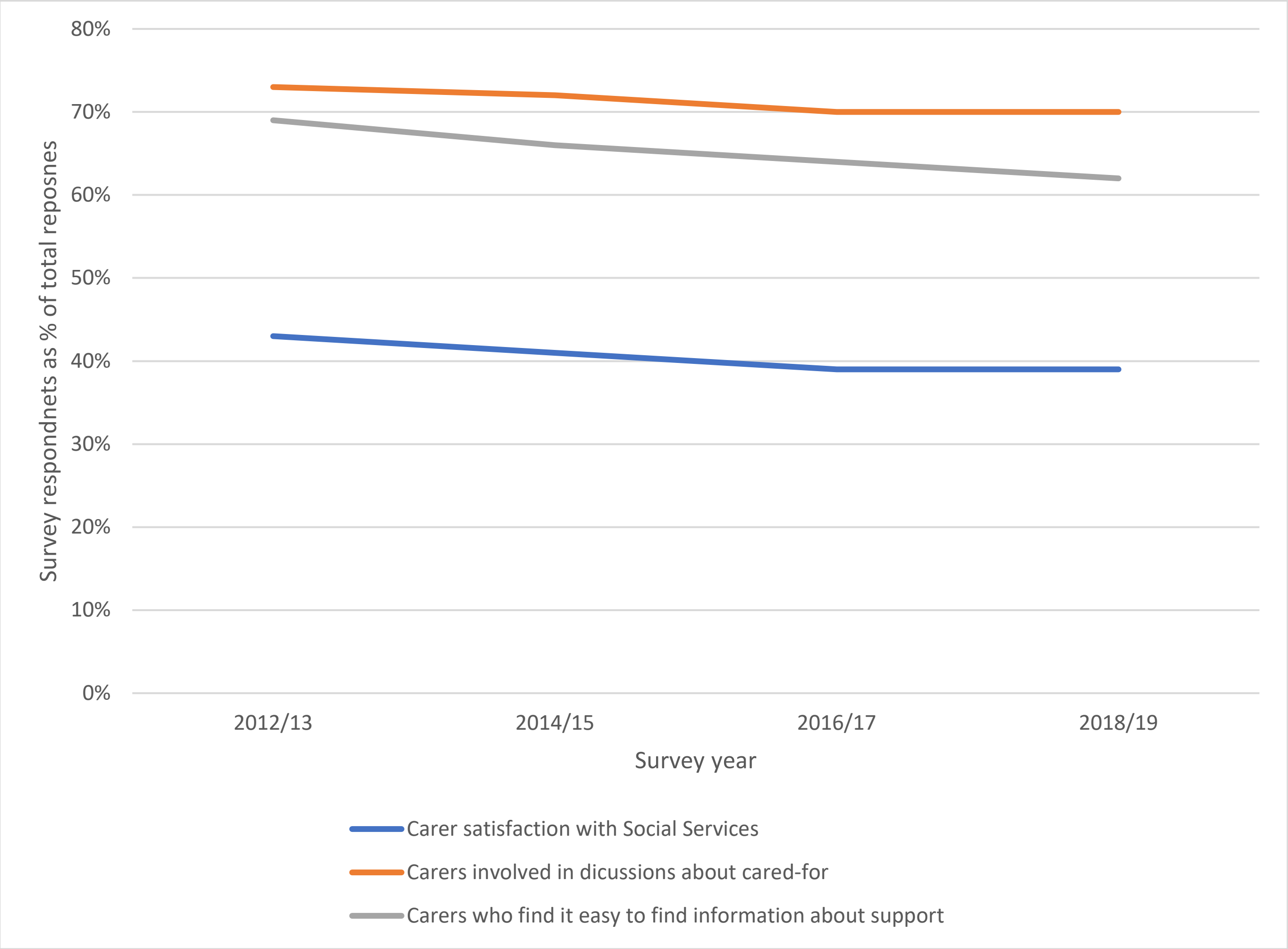
[51] The QoL score used in the ASCOF data set comes from the Adult Social Care Outcomes Toolkit (ASCOT). The ASCOT is a suite of tools developed by the University of Kent to provide a reliable and valid measure of domains that are considered to comprise a person’s QoL. See appendix five for the domains that were used to create QoL domains. These were psychometrically tests and validated with a random sample of carers selected through a survey of people receiving adult social care from CASSRs in England

Source: NHS Digital

4.2.3 Hypothesis three – Carers will report increases in their satisfaction with social services between 2012 and 2019.

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. Findings from the ASCOF outcome measures indicate no measurable improvements reported by survey respondents in neither QoL scores, satisfaction with social services, nor 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. Figure three below shows that carer satisfaction with social services reduced from 43% in 2012/13 to 39% in 2018/19. Hypothesis three was therefore rejected by this analysis.

Figure 3 ASCOF carer reported outcomes 2012 to 2019



Source: NHS Digital

The same position was highlighted in the literature in an 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.[52] Interviewees in my study reinforced 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.

4.2.4 Hypothesis four – 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.

4.2.5 Hypothesis five – Having a PB increases carer 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

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[52] Jones, K., Netten, A., Rabiee, P., Glendinning, C., Arksey, H. and Moran, N. (2014) 'Can individual budgets have an impact on carers and the caring role?', *Ageing and Society,* 34(1), pp. 157-175.

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 37% response rate.

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 1 Two-way tabulation of 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%

Source: SACE survey data 2018/19 survey year

Linear 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 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).[53]

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.

Table 2 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

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[53] Sullivan, G. M. and Feinn, R. (2012) 'Using Effect Size—or Why the P Value Is Not Enough', *Journal of Graduate Medical Education,* 4(3), pp. 279-282.

*,**.*** indicates significance at the 90%, 95% and 99% level, respectively.

R-squared = 0.0218
Adjusted R-Squared = 0.0217

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. They describe the magnitude of the relationship between variables. In the context of this study, 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.

4.3 Phase three: What was the lived experience of receiving a personal budget?

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 guilty 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.

Themes in the qualitative findings speak to some of the tensions created in caring roles, where several 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.[54] [55] [56]

Two overarching themes were created from the interview data. These were:

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

Each theme is presented on a thematic map shown in figure (page 44), with their corresponding sub-themes and codes. Two-way arrowed lines indicate the relationship between sub-themes and themes. 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. Only two out of the 17 participants were offered choice in how the DP could be spent. The remaining participants were informed that carers DPs could only be spent on replacement care. This 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

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[54] Jones, K., Netten, A., Rabiee, P., Glendinning, C., Arksey, H. and Moran, N. (2014) 'Can individual budgets have an impact on carers and the caring role?', *Ageing and Society,* 34(1), pp. 157-175.

[55] Rand, S. and Malley, J. (2014) 'Carers' quality of life and experiences of adult social care support in England', *Health & Social Care in the Community,* 22(4), pp. 375-385.

[56] Woolham, J., Steils, N., Daly, G. and Ritters, K. (2018) 'The impact of personal budgets on unpaid carers of older people', *Journal of Social Work,* 18(2), pp. 119-141.

enjoy an activity or experience as a couple this was not permitted. 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. This section is an edited version of findings from the qualitative data analysis. For a full analysis, please see the thesis.

4.3.1 Theme one: Relationality shapes choice and control

This theme spoke 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.

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.

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

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.

Extract 1: *"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".* [Adult daughter caring for her mother]

Extract 2: *"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".* [wife caring for husband]

Extract 3: *"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."* [wife caring for husband]

Extract 4: *"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."* [husband caring for wife]

Extract 5: *"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."* [husband caring for wife]

4.3.1.2 Sub-theme two: Relationships are important to wellbeing

Relationships and trust between family and paid carers was another important determinant of the extent to which family carers could exercise choice and control. Participants in the study reported that the limited amount of time that their DPs could fund, often meant that 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.

Extract 6*: "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.”* [husband caring for wife]

Extract 7: *“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.”* [Adult daughter caring for her mother]

Extract 8: *“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?”* [wife caring for husband]

4.3.1.3 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 (care) 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.

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.

Extract 9*: “[…] 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.”* [wife caring for husband]

Extract 10: *“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.”* [wife caring for husband]

Extract 12: “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”.* [wife caring for husband]

Extract 13: *“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.”* [Mum caring for adult son]

Extract 14: *“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 right 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.”* [wife caring for husband]

Extract 14 voiced the conflict that can exist when the rights and choices of one person may negatively impact upon the rights and choices of another. The participant 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.

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).

4.3.2 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.

4.3.2.1 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.

Extract 15: *" 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."* [wife caring for husband]

Extract 16: *"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".* [wife caring for husband]

Frustration, confusion, and complexity were terms used by 11 participants to describe their experiences of the carer's assessment process. One participant 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 17: *" 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."*

Extract 18: *"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."* [husband caring for wife]

The interviewee above, later reported that they tried to find out more about their 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. Their extract below 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 19: *"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 on in the interview he added:

Extract 20: *"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!"*

Another challenge with the assessment and support planning process, which was reported by interviewees, 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.

Extract 21: *"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."* [Mother caring for adult son]

Another parent carer in the sample voiced the difficulty of obtaining and/or maintaining employment when you had a full-time caring responsibility.

Extract 22: *"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."* [Mother caring for adult son]

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.

Extract 23: *"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."* [Mother caring for adult son]

Extract 24: *"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."* [Mother caring for adult son]

Four participants used adjectives such as *fighting* and/or *battling* to describe accessing help and support.

Extract 25: *"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."* [wife caring for husband]

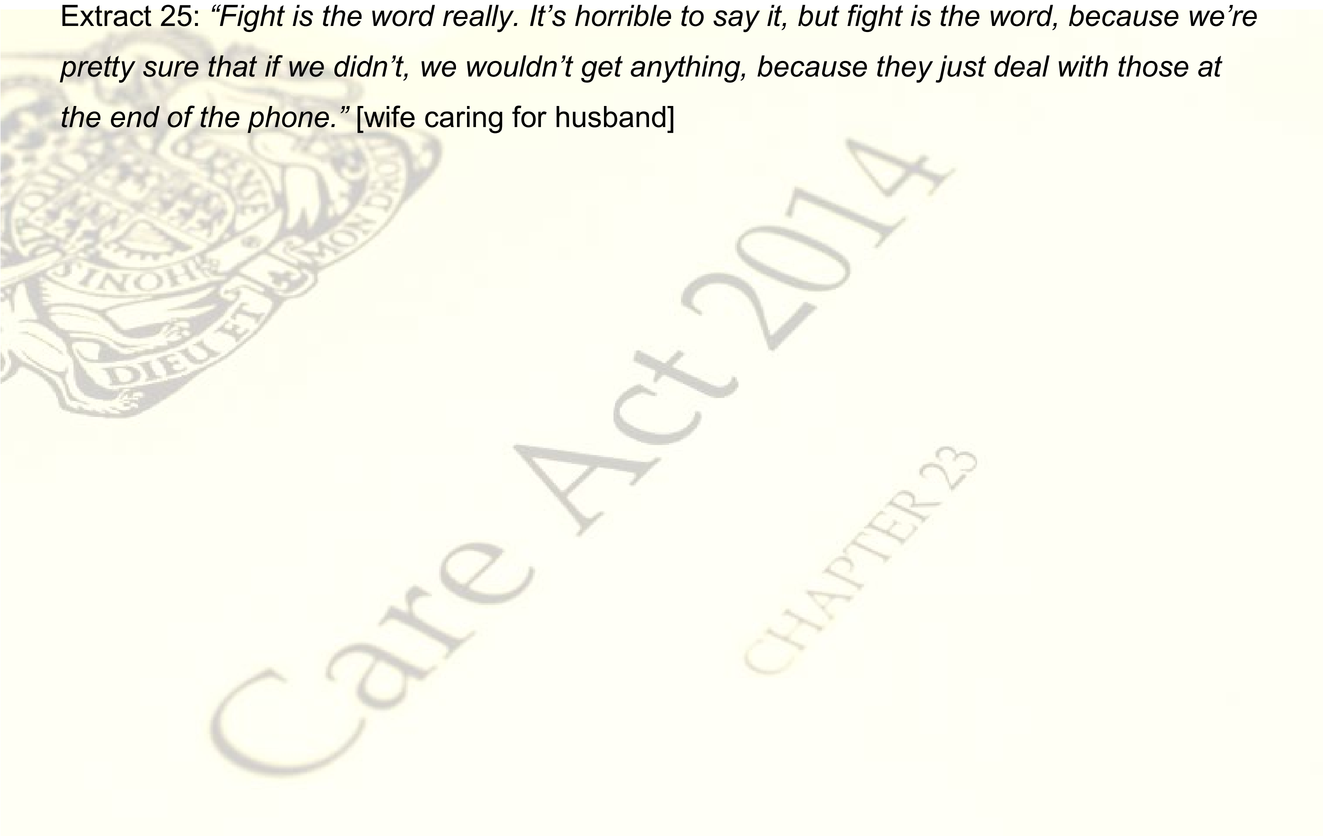
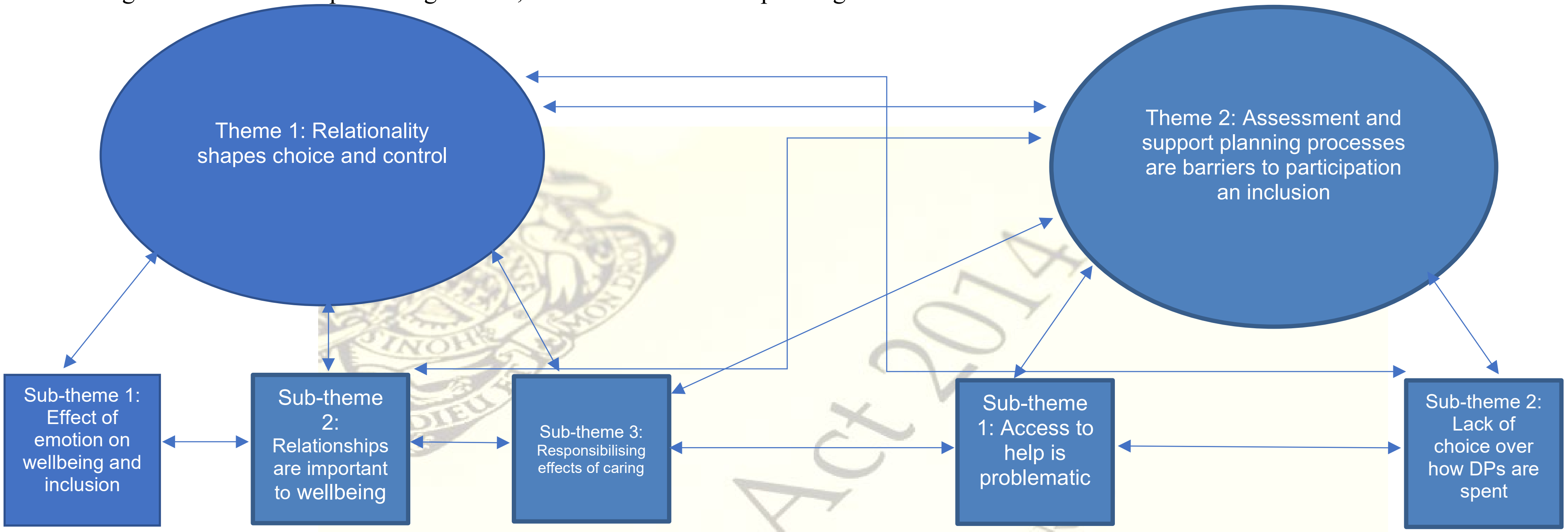


Figure 4 Thematic map showing themes, sub-themes and corresponding codes



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

What can be seen in the qualitative 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.[57] 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.[58] 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

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[57] Conradi, E. (2020) 'Theorising care: attentive interaction or distributive justice?', *International Journal of Care and Caring,* 4(1), pp. 25-42.

[58] Gilligan, C. (1993) *In a Different Voice Psychological Theory and Women's Development.* Harvard University Press.

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 study 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 study proposes 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. [59]

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 was mediated through many other factors that were often beyond their control, such as when and whether the replacement carer would arrive, how long they would stay for, and whether or not the LA would pay for the care, or whether the cared- for would 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 appears an illusory one, both in terms of the qualitative and quantitative findings. The effect of PBs is a shift of 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 is a small pot of money to keep you providing the heavy end expensive care, so the LA does not have to.

5 Conclusions and Recommendations

It is clear from the evidence presented in this study 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 study.

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[59] Arksey, H. and Glendinning, C. (2007) 'Choice in the context of informal care-giving', *Health Soc Care Community,* 15(2), pp. 165-75.

Findings from the analysis shows 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 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) compared to 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.

This research has shown 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 research 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 rather than to empower and/or emancipate carers. 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.

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 in practice, according to the evidence presented in this study. 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 study 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.

This study identifies 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 difference 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
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.

5.1. Micro level change

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. This requires a cultural shift in assessment practice and mindset 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. **Assessment processes that take on a narrative biographical approach would facilitate a fuller understanding of the impact of caring on all aspects of a person's life.**

At the individual level, there needs to be further work done to understand why so few carers receive an assessment of need in England. The fact that more than half of carers who do receive an assessment of need, come away with advice and information only, begs the question – what is the point of a carer's assessment? Exploring barriers with social work practitioners would be one to achieve this. From my own social work practice, one barrier I remember is that carer's assessments were not counted in workload management models, therefore it became practically challenging to carry out assessments for carers when the time they took was not factored into the number of cases you held.

5.2 Meso level change

Family budgets (or integrated personal 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.

Combining service user and carer personal budgets may provide a number of benefits for both service user and their carers. It may lead to increased flexibility in how funding is used. This can allow for more tailored support packages, with funds being used to purchase services or support that is specifically tailored to the needs of both the service user and their carer. This would support the whole family approach to assessment and support issues under the Care Act (2014).

This may in turn lead to improved outcomes for carers if their voices are seen as an integral part of a joint assessment process. The statutory guidance acknowledges the benefits of providing combined personal budgets. Specifically paragraph 11.38 states: *“Local Authorities should consider how to align personal budgets where they are meeting the needs of both the carer and adult needing care concurrently.”*

Overall the guidance provides a clear indication that LAs are able to provide combined personal budgets for service users and carers as part of wider commitment to promoting integrated and tailored care and support.

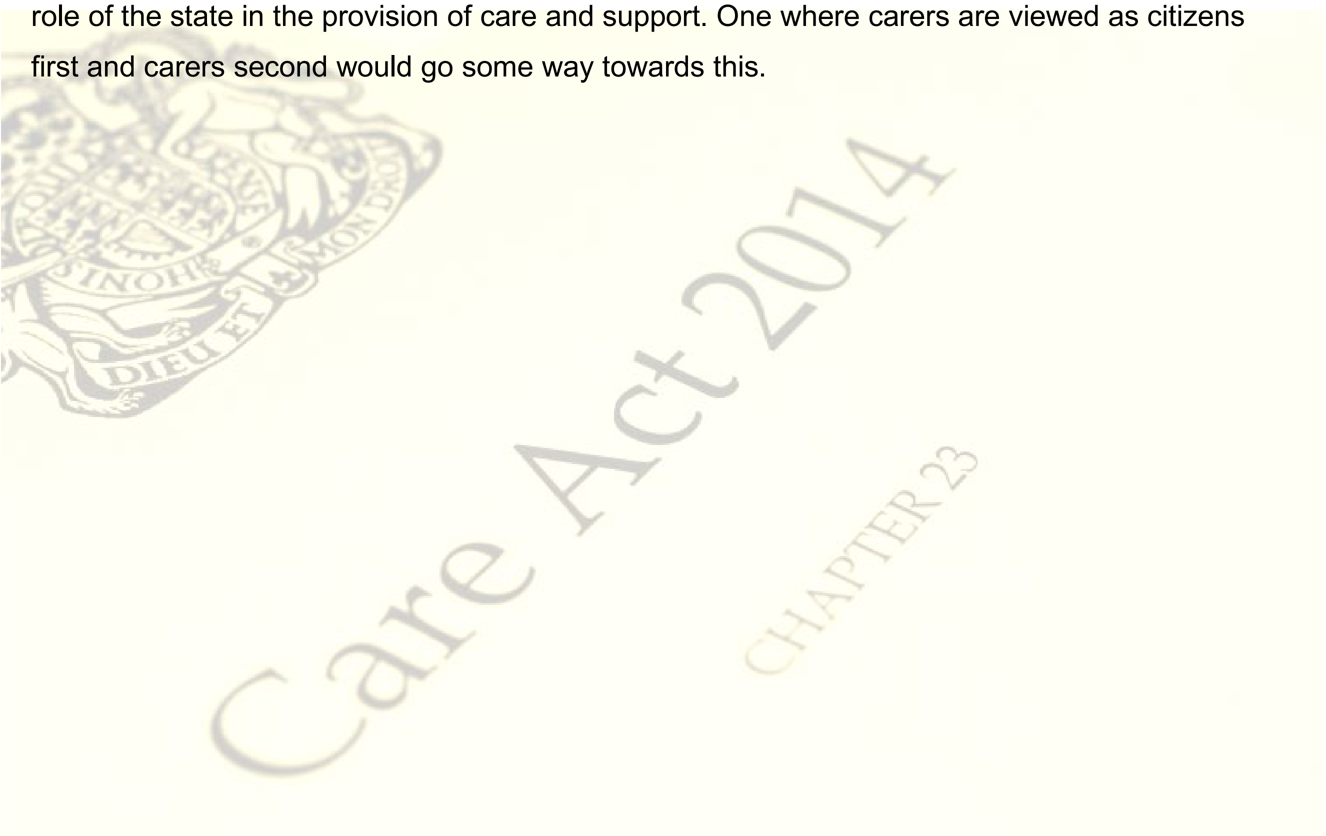
5.3 Macro level change

At the macro level we need to have discussion and debate about caring from a human rights and equalities perspective. Society needs to ask itself what it can expect from families with caring responsibilities that acknowledges that human rights belong to everyone irrespective of caring roles. Caring can no longer be viewed through the lens of care and support and purely the responsibility of public bodies like Local Authorities .

Participation and inclusion of carers in society needs to be reconceptualised as both a relational and political process which bridges was are often characterised as two competing theories of care.

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

A reimaging of the role of carers in society and their relationship with the government where care is viewed as shared responsibility requires a shift in ideological thinking about the role of the state in the provision of care and support. One where carers are viewed as citizens first and carers second would go some way towards this.



6 Appendices

Appendix1: 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

Appendix 2: Methodology

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. [60] [61] [62]

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, which 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.

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[60] Bacchi, C. L. (1999) *Women, policy, and politics : the construction of policy problems.* London: Sage.

[61] Bacchi, C. and Goodwin, S., (2016) *Poststructural policy analysis*. New York, New York: Palgrave Macmillan.

[62] Shaw, S. E. (2010) 'Reaching the parts that other theories and methods can't reach: how and why a policy-as-discourse approach can inform health-related policy', *Health (London),* 14(2), pp. 196-212.

Appendix 3: WPR questions

1. What’s the problem of caring represented to be in the Care Act (2014) guidance?
2. What assumptions underlie this representation of the problem?
3. How has this representation of the problem come about?
4. What is left unproblematic in this problem representation? What are the silences? Can the problem be thought about differently?
5. What effects (discursive, subjectification, lived) are produced by this representation of the problem?
6. How can this representation be disrupted or replaced?

Appendix 4: Carer Eligibility table

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. "*

Appendix 5: 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[63]	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)

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[63] Scale developers do not use this ASCOT domain to form the ASCOF QoL score

Appendix 6: Data sets used in the study

	TYPE OF ANALYSIS	SAMPLE SIZE	VARIABLE TYPE	HYPOTHESES
DATA SET	Descriptive – measures of central tendency	2018/19 survey year N=292,360, n=136,095[64]	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[65]	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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[64] ACOF and SACE samples are identical. The survey elements of the ASCOF are taken from sample respondents to the SACE survey.

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

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			

Appendix 7: Preliminary themes and their corresponding codes

Care Act 2014

CHAPTER 23