

# Supporting carers following the implementation of the Care Act 2014: eligibility, support and prevention

## The Carers in Adult Social Care (CASC) study

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End-of-project report

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2020

## **DISCLAIMER**

This study/project is funded by the National Institute for Health Research (NIHR) Policy Research programme project reference PR-R14-1215-21008/Supporting carers following the implementation of the Care Act 2014: eligibility, support and prevention. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

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## 1.1 STUDY OVERVIEW

The Care Act 2014 gave carers in England new rights to the assessment of their needs and clarified their entitlements to public support, aiming to make support for carers more consistent and accessible. The primary aims of this study were:

- To understand local authority processes and approaches for assessing and meeting the care needs of carers in England, and to examine the extent to

which they changed following the implementation of the Care Act 2014.

- To evaluate the support provided to carers post-Care Act 2014.

The study adopted a mixed-methods approach, combining quantitative and qualitative analyses and individual and area-level data to carry-out the research activities summarised below.

## 1.2 RESEARCH ACTIVITIES, METHODS AND FINDINGS

### 1.2.1 Contextual literature review

The research team carried out a contextual literature review focusing on analysis of the 2013/14 parliamentary debates available online from Hansard. The purpose of this review was to analyse the policy and political context within which the Care Act was developed to better understand how its aims regarding carers had been drafted and debated.

The debates indicated an expectation that the Care Act Bill would constitute a historic reform that would strengthen the rights of carers to access support, putting them on the same legal footing as those they care for. There was near unanimous agreement on the strategic importance of supporting carers as a policy goal. A key feature of the reform was the use of the well-being principle for carers as well as for those cared for. Prominent mention was made of the importance of the NHS in supporting carers, as well as of the need to provide adequate information and advice to carers.

### 1.2.2 Patterns of carer support in England: variations across English local authorities and pre-post 2014 Care Act

A key objective for the study was to assess whether the Care Act had led to significant increases in local authority support for carers. Quantitative analyses were conducted exploring variations across local authorities and through time in carer assessments, carer support packages and expenditure as well as in carers' satisfaction with statutory support. Regression models were used to test the impact of the implementation of the Care Act on local carer support controlling for other factors likely to influence provision (such as the socio-demographic profile of local authorities).

Unadjusted figures showed numbers of carer assessments in England to have declined steadily since 2009/10, falling from approximately 450,000 per year in 2009/10 to just over 350,000 per year in 2017/18 – a trend that was broadly

mirrored in terms of numbers receiving services and information. Statistically significant decreases in numbers of carers receiving assessments and/or support were confirmed by multivariate regression results. Similarly, carer-related expenditure was found to have decreased in the years following the Care Act, whereas overall social care expenditure increased by 3% in cash terms (1% in real terms) from 2015/16 to 2016/17, carer expenditure fell by 6% in the same year.

Our analyses of individual-level data from the Survey of Adult Carers in England suggest that, post-Care Act, ongoing support for carers was concentrated on carers providing more intensive levels of care. We also found an increase in the proportion of carers receiving information or advice as opposed to ongoing support services. A small but significant reduction in satisfaction with support was found, which remained statistically significant when controlling for client characteristics. However, the way that data are collected do not permit comparisons between levels of support provided to working age and older carers.

The results of our quantitative analyses were therefore surprising given the general perception that the Care Act would lead to increases in assessments and better access to support for carers.

It is likely that the capacity of local authorities to realise the policy ambitions of Care Act was mediated by the significant budgetary constraints they experienced. In addition, some data limitations may partially explain the observed trends: local authority returns do not differentiate between assessments of new carers and of carers already known to services, so it is difficult to estimate precisely the number of new carers assessed following the implementation of the Care Act. Moreover, some of the increased involvement of the voluntary sector in carers' assessments and support might not be reflected in the returns submitted by local authorities.

The quantitative analysis was complemented by qualitative and process

evaluations to further understand the implementation by local authorities of the Care Act and its impact on patterns of support for carers.

### **1.2.3 Review of local authority websites across England**

The Care Act placed new responsibilities on local authorities around their provision of information and advice relating to care and support. Given the high proportion of carers reported to use the internet as a source of information, the study aimed to investigate the extent to which local authority online resources provided carers with information about eligibility for support, local authorities' legal responsibilities and the availability and charging arrangements for services. We therefore reviewed 79 local authority websites and carried out an in-depth analysis of information systems in four local authorities.

By 2019 almost all the websites reviewed had been updated to ensure that they were compliant with the 2014 Care Act. This represented an improvement when compared with a smaller scale pilot exercise in 2017 which revealed that some local authority websites still referred in their public documents to pre-Care Act legal frameworks. We found noticeable improvements regarding the availability of information about support/services, in particular covering universal services, safeguarding, as well as the provision of external links to other sources of support. However, despite improvements through time in the online information provided for carers by local authorities, by the end of the study there were still websites that appeared not to provide enough essential standalone information to empower carers to receive appropriate support from their local authority or to access universal services provided through other organisations (e.g. the NHS and/or the voluntary sector).

In terms of comprehensiveness, a third of 79 websites reviewed in 2019 were rated as "above average" based on the criteria agreed by the research team.<sup>1</sup> The word 'average' here is used in the sense of

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consumer ratings, and not the arithmetic mean. It was used to mean that the websites provided information which was above/below the “typical” level and quality of information for carers. Four fifths included a definition of a ‘carer’ and just over half referred to the Care Act. Nearly all websites referred to a carer assessment, although only half referred explicitly to carers’ rights to an assessment, with a similar proportion providing working links to a self-assessment tool. 42% of websites referred to support for carers of adults funding their own care. Although the eligibility criteria in the Care Act state that the carer’s needs for support arise because they are providing necessary care to an adult, it is worth noting that over 90 percent of the websites sampled mentioned young carers as a group who could access support, albeit this would be under different legislation.

The websites reviewed varied significantly in the content and organisation of the online information on carer support. Such variability does not seem to be justified on the grounds of the tailoring of the information provided to local care systems and is likely to be leading to differences in access to statutory support for carers across England.

#### **1.2.4 Understanding local policies and processes for supporting carers: process evaluation**

The study carried out a process evaluation in four local authority sites to gain an in-depth understanding of the policies and processes involved in supporting carers (e.g. case-finding, needs assessment, and care planning), and to assess the extent to which they had been affected by the implementation of the 2014 Care Act.

Interviews were carried out with 17 key informants (professionals involved in carer assessments, policy representatives, heads of services, commissioners and voluntary sector organisations) across four local authorities between 2017 and 2018 and were explored using thematic analysis. We collected information about: local goals associated with supporting carers; intended outcomes of supporting carers; local strategies to assess the needs of, and support of carers; services provided to carers; coordination of efforts between the

local authorities and other agencies in the design, delivery and assessment of services and if/how these changed following the Care Act.

The evidence collected suggested the Act had legitimised the belief that carers need and deserve help in their own right, with an increased emphasis on identifying carers and supporting carers’ health and wellbeing. However, tensions were noted between the genuine desire to support carers’ wellbeing, for instance through improving the availability of carer services in the voluntary sector and the local authority need to manage demand (and associated attempt to divert people away from statutory services) given existing financial pressures. Key respondents reported that the collaboration with voluntary sector organisations increased following the Care Act implementation, particularly related to their involvement in the provision of low-level preventative services for carers. Collaboration between local authorities and NHS partners (Clinical Commissioning Groups (CCGs), GPs) was also reported to be vital for the development of effective support for carers and revolved around jointly developed Carers’ Strategies and projects.

In line with the results of our quantitative analyses, all areas reported that the significant increases in demand for carers’ assessments that had been expected prior to the implementation of the Act had not materialised, and mentioned information and advice as the most frequently provided service by local authorities, together with the funding of carer support groups. Access to replacement services for help provided by the carer was reported to be very limited.

#### **1.2.5 Carers interviews and carers survey**

Using a mixed-methods longitudinal approach, we carried out a follow-up survey of 157 working carers building on two surveys conducted in 2013 and 2015. The survey elicited carers’ views regarding access to different types of services (including replacement care) and the ability of the post-Care Act care system to support employment outcomes for carers as well as their caring role. In addition, we carried out 11 follow-up in-depth telephone

interviews with a sub-sample of respondents who had completed questionnaires.

Whereas the receipt of services to care recipients in 2013 was found to be associated with an increased likelihood of carer employment in 2015, no such correlation was evident in 2017. Interviews suggested levels of service receipt did not keep pace with increasing carer and care user needs, due in part to low rates of assessments and reviews.

Despite the positive influence of flexible working arrangements, the findings suggested many carers were unable to continue working once these working options had been exhausted and caregiving responsibilities increased. Particularly in the 2017 follow-up sample, carer ill-health was found to contribute to leaving employment, which may be associated with carers themselves becoming older as well as the longer-term impact on physical and mental health status of providing care.

### **1.3 KNOWLEDGE EXCHANGE AND DISSEMINATION**

We engaged closely with carers, practitioners and local and central government officials throughout the study. An Advisory Group comprised of 5 carers and 4 practitioners met three times during the study, helping researchers to consider aspects of research design and content as well as the interpretation of study findings. Meetings were also conducted with policy leads and analysts from the Department of Health and Social Care and the Department of Work and Pensions to discuss methodology and ongoing findings, as well as a series of feedback sessions with individual local authorities to disseminate findings and assist in the interpretation of evidence.

The study generated a series of publications on the different components of

the research. At the time of writing, two papers had been published, a further paper accepted for publication subject to changes and four papers were being prepared for submission.

Interim and final findings were presented throughout the life of the project at government departmental meetings, stakeholder workshops and research conferences. Additional presentations from the research team took place in 2020 (for example for social workers' continuing professional development (CPD)) and more are planned for 2021. The local authorities and the carer organisations involved in the study have used the findings of the study to inform the development of local carer support services and of their local carer strategies.

### **1.4 CONCLUSIONS**

Our evaluation suggests that the impact of the 2014 Care Act on carers in England could be described as a combination of conceptual achievements and practical challenges. The improved clarity about the roles and responsibilities of the state towards carers was notable and widely

welcomed by social care stakeholders. However, the impact of strengthened carer rights appears to have been limited by the requirement for local authorities to keep within budget, and as a result these rights have not led to greater access to support for carers.

# STUDY OBJECTIVES AND METHODOLOGICAL APPROACH

## 2.1 OBJECTIVES

The Care Act 2014 gave carers in England new rights to the assessment of their needs and clarified their entitlements to public support. It aimed to make support for carers more consistent and accessible. In this light, the aims of the study were two-fold:

- To understand the processes and resources for assessing and meeting the care needs of carers in England, and to examine the extent to which they changed following the implementation of the Care Act 2014.
- To evaluate the support provided to carers post-Care Act 2014.

Within the broad aims outlined above, the study objectives were to address the following questions:

- How do English local authorities identify,

assess and respond to carers' needs following the implementation of the Care Act 2014?

- Which approaches are used by local authorities to identify carers at risk?
- How are carers' needs considered when they first contact local authorities?
- What models are used for triaging and assessing needs? What is the role of self-assessment?
- What role is played by the community and voluntary sector in the assessment process and the design of care and support for carers?
- What is the relationship between carers' needs and different types of support?
- What are the consequences for costs and outcomes of different forms of support for carers?

## 2.2 RESEARCH METHODS

The objectives listed above were addressed through a combination of quantitative and qualitative evaluation methods. Overall, qualitative evaluation methods were used to explore how the carers' support system was organised (e.g. needs and risk assessment, first point of contact systems, interaction between local authorities and the voluntary sector) and the extent to which these processes had changed following the implementation of the Care Act. The study used quantitative methods to explore the effect of the changes in the organisation of carers' support system on carers (e.g. changes in the numbers of carers assessed and receiving services, changes in levels of satisfaction with the care system).

The study therefore adopted a mixed-methods approach, using a combination of individual and area-level data to carry-out the following research activities.

**Contextual literature review.** We conducted documentary analyses of Hansard articles of the 2013/14 parliamentary debates on the Care Bill's provision for carers. Although this was not part of the original scope of the study, during the course of the project it became evident that such a documentary analysis added useful contextual information to the project. Specifically, the purpose of this review was to describe the policy context within which the Care Bill (later Act) was drafted and debated to better understand how its aims regarding carers had been developed.

### **Mapping of local support systems post-Care Act.**

The first research objective of the study was to conduct a review of local authority websites to extract information about local definitions of carers, options for carers for engaging with local services, and types of support offered to them. Where authorities contracted out services or the first point of contact role was undertaken by Carers' Centres or similar organisations, we also aimed to review information provided in these organisations' websites. The Care Act's emphasis on the availability of advice and information underlined the importance of this element of the Care Act implementation. We also aimed to complement the data gathered from websites by engaging with professionals from local authorities and other relevant organisations.

If any information from the websites included in the website review was unclear, we aimed to clarify and complement the data with telephone interviews with professionals from the local authority and other relevant organisations. Upon consideration, it became clear that it would be difficult to identify a person responsible for website content and interview them. Instead, a feedback session was held with representatives of the local authorities taking part in the process evaluation to gather their views on the findings. This provoked discussion about the extent to which variation in the format and content of websites was necessary and desirable and the potential to improve outreach to so-called 'hidden' carers (e.g. individuals caring for friends/relatives with social care needs but that do not self-identify as "carers" and therefore are unlikely to come into contact with formal support services) via the use of images highlighting the diversity among carers.

Following the analyses of local authorities' websites and the content of online information for carers, it became apparent that a more in-depth examination of website content of a few selected local authorities would add more detailed understanding to the project. Therefore, we added such an in-depth examination or mapping of websites in four local areas to our analyses.

### **Analysis of predictors of local variations in carer support, and of changes in support post-Care Act.**

We proposed to complement the local mapping exercise with quantitative analyses exploring the variations in the type and amount of carer support commissioned by English local authorities. These analyses aimed to investigate whether local characteristics explain a significant proportion of the variability in local patterns of carer support, and controlling for such characteristics, to test for changes in carer support levels (e.g. numbers of carer assessments; numbers of carers receiving support) following the implementation of the Care Act 2014. These analyses aimed to combine area-level and individual-level data on patterns of carer support with publicly available data about local area characteristics (e.g. characteristics associated with likely demand for carer services).

We used quantitative methods to explore the link between features of the local care systems and local levels of carer support, controlling for local socio-economic and demographic factors. Indicators of local authority carer support (e.g. carers contacted, assessments undertaken and outcome of assessment, types of support provided) were to be collected at the area level from the Short and Long-Term Support (SALT) returns and at the individual level from the Survey of Adult Carers in England (SACE). We planned to combine the 2014-15 and 2015-16 SALT data (or 2016-17 in the case of SACE data), to test whether the implementation of the Care Act 2014 had been associated with changes in local levels of carer support, and the extent to which any changes varied between types of authorities.

### **Process evaluation of local authority carer support systems.**

The study sought to complement the national analyses with local in-depth information by purposefully sampling up to five authorities with different socio-economic backgrounds and patterns of carer support to carry out an in-depth process evaluation of local carer assessment and support systems. In the event, one area withdrew from the study after its capacity to contribute was affected by increased demand for its services

arising from a major incident. We aimed to examine the mechanisms used and approaches to case-finding, needs assessment and care planning for carers. We proposed to use case study framework analysis methods in each partner area to gain an in-depth understanding of the local policy and service structures and processes, to understand "how" and "why" decisions are taken locally about the allocation of resources and the design of the support system. We aimed to use a combination of policy documentation and interviews with professionals involved in the provision of carers' services and assessments (including any local authority carers' lead with a policy strategy role, NHS Clinical Commissioning Group carers' lead, care managers, Director/Deputy Director Adult Social Services, local carer voluntary organisation manager) to examine the following questions:

- Which criteria are used by local authorities to define who is a carer? How is the definition of carers in the Care Act implemented on the ground?
- Which processes are used locally for identifying such carers?
- How are carers' needs assessments carried out? (By whom? Are Carers Centres involved? Use of self-assessment?)
- What types of support are offered to which carers, and how are they expected to contribute to prevent, delay or reduce individuals' needs for care and support?
- How are services designed to support carers' wellbeing, including their opportunities for paid work?

For all the questions above, we aimed to understand the changes brought about by the implementation of the Care Act 2014.

The final sample included four local authorities covering the main categories of local authorities in England, specifically metropolitan (Midlands), two London boroughs, and a non-metropolitan county (East of England).

**Evaluation of local carer support.** We planned to assess the benefits and costs of carer support services in the local authorities participating in the process evaluation. Our initial plan was to base the evaluation on local administrative data systems, by matching individual level-data about carers'

needs and service packages from the local authority assessment and financial administrative records to information from the Survey of Adult Carers in England (SACE).

We hoped to evaluate a small number of support schemes in the local authorities involved in the process evaluation. We planned to build on our experience evaluating social care services using local administrative data from "Developing a Framework for Evaluating Prevention in Social Care", a study funded by the NIHR School for Social Care Research.

Through the life of the study, it became apparent that local authorities' information systems did not record information about carers with sufficient granularity to enable this type of evaluation based on their data. In particular, we found that very little information was recorded in statutory systems about the characteristics of carers, about the support they received and about relevant carer outcomes. In addition, the local authority administrative systems were surprisingly unable to link information about carers to information about the person being cared for even if he/she received support from the council.

The limited information held by local authorities about the carers they support is explained to a large extent by the extensive involvement of external organisations (and in particular voluntary sector carer support organisations) in the carer assessment and support activities. These organisations provide regular updates of aggregated data back to local authorities in the form of periodic "returns". We also engaged with several of these carer organisations to explore the possibility of using their data systems for the evaluation, but this was not possible due to Information Governance requirements and the limited nature of the data systems in place.

As a result of these data challenges, we focussed our individual level analysis of the relationship between carer needs, support and carer outcomes on data pooled from the Survey of Adult Carers in England (SACE) before and after the implementation of the Care Act, and on the primary data collected by the study through its extension of a carer survey, as is further discussed below.

With respect to the data from the Survey of Adult Carers in England, the research team applied to NHS Digital's Data Access Request Service (DARS) for access to the extended version of the dataset, which contains greater details about the characteristics of the carers surveyed. However, the time involved in processing our application made it unfeasible for the study to gain access to the data in time for its use in its analyses. This meant that the analyses were carried out using the less comprehensive, publicly available version of the Survey of Adult Carers in England.

**Carers survey.** The study extended a longitudinal survey (the Overcoming Barriers survey) of carers previously carried out by team members which collected data on support and services and carers' employment at baseline in 2013 (Time 1) and at follow-up in 2015 (Time 2) (Brimblecombe *et al.*, 2017, 2018; Pickard *et al.*, 2018).

This was an important study in terms of its scale and its longitudinal nature. Data were collected on support and services and carers' employment using telephone

interviews from 373 carers at baseline and from 256 carers at follow-up. In this project, we sought approval to conduct a third follow-up for the purposes of this research to look at employment outcomes in early 2017. The Time 3 questionnaires aimed at repeating key questions from Times 1 and 2 on support and services received, and if needed, by both carer and the person they support; these covered carers' assessments; employment; intensity of caring; and sociodemographic information.

**Research ethics.** The study received Health Research Authority Social Care Research Ethics Committee (SCREC) ethical approval, SCREC reference number 17/IEC08/0029.

The LSE Research Ethics Review Checklist and Data Management Plan were completed in accordance with the Committee's requirements, after completing the review checklist it was deemed that adequate safeguards in relation to any ethical issues were in place and LSE information security guidance was followed.

## 3.1 CONTEXTUAL LITERATURE REVIEW

The research team carried out a contextual literature review focused on the text from parliamentary debates focused on the passing of the Care Act, available online from Hansard. The Bill included reforms to the legislative framework for responsibilities to support family or friends providing substantial care to an adult with needs for care.

This additional component to the study analysed Hansard reports to synthesise key themes, contextualised by other materials referenced in Parliamentary debates or that commented on the debate in order to elicit politicians' ambitions for the legislation and how any criticism of its provisions was managed and articulated. Our aim was to identify the stated intent of the Care Act 2014 to inform our evaluation of its impact on carers.

### 3.1.1 Methods

The inclusion criteria (time period and focus on debates) for the review of the Hansard reports were determined in order to cover the Parliamentary activity relevant to the passage of the Care Act's through both Houses of Parliament. The research team covered the time period March 2013 to May 2014, and identified debates using search terms in the Hansard search engine (such as 'carers', 'Care Bill'). Hansard material from both Houses of Parliament was included in the analyses but not other material from Parliamentary Committees and All-Party Parliamentary Group meetings. Additionally, for background, we examined some of the government documents that contributed to the debate and research investigating the early years of the Care Act.

### 3.1.2 Key themes of Parliamentary debates

The main findings from our analysis of Parliamentary debates were:

- The debates indicated an expectation that the Bill constituted a historic reform that would strengthen the rights for carers to access support, putting them on the same legal footing as those they care for.
- There was near unanimous agreement on the strategic importance of supporting carers as a policy goal.
- The Bill was perceived to build on important progress made through previous legislation in areas such as prevention, personalisation of services, and carer recognition and support in the National Carers Strategy.
- A key feature of the reform was seen to be the use of the well-being principle, which was to be applied to carers as well as those supported or cared for through the Act.
- The debates highlighted a lack of clear delineation in the Bill between what is a carers' service and what is a service for an older or disabled person. It was argued during the debates that such a lack of clarity might affect local charging policies, enabling local authorities to charge service users for services such as replacement care, in contrast with other services (such as information and advice) which were provided free of charge.
- Parliamentary debates often alluded to the local authorities' financial situation as an important contributory factor

explaining local policies for carer support, and in particular for seeing replacement services as service for people in need of care and support.

- The debates highlighted the importance of information and advice services for carers often using politicians' own experiences.
- The debates often alluded to the importance of the NHS in supporting carers. Some politicians highlighted the potential role of NHS agencies in helping to identify carers, called for a greater

NHS funded support for carers, and advocated for improvements in collaboration between NHS and LAs in supporting carers.

- The Parliamentary debates did not generally question the need for families to provide care or discuss the potential of carers to refuse to take on a caring role. Rather, the caring role of families was taken for granted and/or explicitly commended during the debates.

The full findings from this analysis are available in Manthorpe et. al (2019).

### 3.2 PATTERNS OF CARER SUPPORT IN ENGLAND: VARIATIONS ACROSS LOCAL AUTHORITIES AND PRE-POST 2014 CARE ACT

The guidance accompanying the Care Act (Department of Health, 2016) made local authorities responsible for:

- Identifying carers that might have support needs that are not being met;
- Offering an assessment where a carer appears to have needs, regardless of the level of caregiving provided or the needs of the person cared for; and
- Determining appropriate levels of support using eligibility criteria in line with the processes used for adults with care and support needs.

As a result of enhanced rights to an assessment and the introduction of more explicit national minimum eligibility criteria to support for carers, the Act was expected to lead to a substantial increase in the numbers of carers approaching local authorities for support. A government impact assessment published during the consultation process thus estimated that the Act would generate an additional 270,000 carer assessments in the first year, rising to a steady-state increase of 360,000 assessments per year by 2017/18, due to expected 'slow-burn' effects as national and local awareness-raising activities took effect (Department of Health, 2014).

In this context, a key objective for the study was to assess whether the Care Act had indeed led to significant increases in local authority brokered (or otherwise) support for carers. The study therefore complemented the analyses of local information systems, process evaluation and carer survey and interviews described

below with a quantitative analysis of patterns of support for carers in England based on aggregate and individual-level data. This analysis aimed to understand the extent of variability in levels of support across areas in England, and to assess where these levels of support and carer outcomes had changed significantly following the implementation of the Care Act. Our analysis was structured around the following steps:

- **Longitudinal analysis of numbers of unpaid carers and of intensity of unpaid care provision in England**, to assess changes through time in underlying levels of potential demand for carer support. This analysis was meant to help us interpret the changes in carer support activity through time in England by providing a reference/benchmark trend of the numbers of carers in England through time.
- **Quantitative analysis of variations through time and across areas in local authority brokered carer support**: numbers of assessments, numbers of carers receiving support, and levels of expenditure on carers' support.
- **Quantitative analysis of levels of satisfaction with carer support**, across areas and through time.

#### 3.2.1 Data and methods

Our analyses were based on individual and area-level quantitative evidence about levels of carer assessments, carer support and carer satisfaction with statutory support, and on indicators of factors likely

to be associated with variations in those, such as indicators of local demand (e.g. socio-demographic profile of local authorities, need related characteristics of individual carers).

Evidence about local authority commissioned carer support was collected from the activity and financial returns submitted annually by English authorities and published by NHS Digital. These provide authority-level data on numbers of carer assessments, information and support (2007/8 to 2017/18) and corresponding expenditure (2014/15 to 2017/18). The study focused on three measures:

- Numbers of carers assessed (jointly or separately) (based on RAP – Referrals, Assessments and Packages of Care – and SALT – Short and Long Term Support – returns);
- Numbers of carers receiving support (carer-specific services, information or signposting from RAP and SALT returns);
- Gross current carer-related expenditure (direct payments or other, from ASC-FR – Adult Social Care Financial Returns).

Important caveats exist around the consistency of activity measures between time points. In April 2014, the SALT returns replaced RAP as the reporting mechanism for Adult Social Care Activity levels. There are many commonalities between the two, but also key differences in accounting practices. In particular, the SALT return required the reporting of numbers of carers in contact with adult social care departments (in local authorities) but not receiving an assessment during the period, whereas numbers 'not assessed' in RAP years refer solely to those offered but refusing assessment. Rates of provision can therefore be more reliably compared within, rather than between, data series. Carer support was only recorded as an expenditure category from 2014/15 onwards in the Adult Social Care – Finance Returns (ASC – FR). In earlier years, the equivalent expenditure reported in the social care financial returns provided by local authorities (the PSS-EX1 returns)

would typically be recorded against the eligible care recipient, and thus could not be disaggregated.

Our study combined descriptive analyses with regression analyses which controlled for confounding effects in order to explore changes in the patterns of provision, pre- and post-Care Act, at area and individual levels. In addition to changes in targeting practices, rates of support are likely to be determined by factors associated with the demand for and availability of informal care – including population size, dependency, living arrangements and the availability of formal support. To control for the effect on variability in carer support of local characteristics, a series of multivariate regression models (generalised estimating equations) predicting local levels of carer assessments, support and expenditure were estimated controlling for such factors. As well as allowing us to standardise for non-Care Act related influences on patterns of carer support through time, and therefore to derive an "adjusted" estimate of the change support following the implementation of the Act, these models provided interesting evidence about the factors driving variations in carer support across English authorities (see Table 1).

To assess the impact of the Act on the perceived quality of assessments and care *among carers receiving local authority support*, individual-level data were pooled from the 2012/13, 2014/15 and 2016/17 waves of the Survey of Adult Carers in England (SACE) (NHS Digital, 2017). The survey provides responses to questions about carer and care user needs, support and perceptions of the quality of support received based on sample of carers randomly selected by local authorities. Specifically, the indicator used in the analysis measured carers' satisfaction with the services provided to themselves or to the 'cared-for' person during the previous 12 months. An Ordered Probit model was used to identify levels of satisfaction according to a seven-point scale graded from "extremely satisfied" to "extremely dissatisfied", controlling for differences in the characteristics of carers and 'cared-for' person between time points.

**Table 1: Factors associated with population-standardised levels of carer assessment, support and service expenditure**

	Carer assessments	Carers receiving information or support	Carer-related service expenditure
Population characteristics			
Population size (millions)	-0.26**	-0.15	
% adults aged 18–64 receiving Carer's Allowance	10.54**	17.56***	27.23*
% population aged 85+	12.52**	12.56***	
% adults aged 65+ with Attendance Allowance	2.97***	3.18***	-7.24
% adults aged 65+ married/in a civil partnership	2.61***	2.19***	-1.26
Social care expenditure (£ millions)			
Total net ASC expenditure per capita (unit cost standardised)	0.16	0.06	1.11***
Social care clients per capita	3.56***	3.06***	-8.35
Financial year (reference 2014/15, prior to Care Act) (£ millions)			
2007/8 (pre-Care Act)	0.11	-0.04	
2008/9 (pre-Care Act)	0.19***	0.03	
2009/10 (pre-Care Act)	0.26***	0.15*	
2010/11 (pre-Care Act)	0.22***	0.13*	
2011/12 (pre-Care Act)	0.22***	0.12*	
2012/13 (pre-Care Act)	0.18***	0.06	
2013/14 (pre-Care Act)	0.22***	0.10***	
2015/16 (post-Care Act)	-0.16***	-0.05	-0.16
2016/17 (post-Care Act)	-0.23***	-0.11	-0.36***
2017/18 (post-Care Act)	-0.26***	-0.11	-0.42***
Model summary			
Pseudo R <sup>2</sup>	0.28	0.18	0.10

Note: \*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.001

### 3.2.2 Time trends in demand for local authority support for carers

Judging the adequacy of the level of support provided by local authorities to carers requires us to have a clear understanding of the numbers of carers that might require such support. However, there is significant uncertainty regarding overall trends in the numbers of carers in

England and in the nature and intensity of the support they provide, despite the inclusion of informal care indicators in major population- and household-level surveys. Challenges to the measurement of unpaid care have been associated with the low levels of self-identification by people providing support with the term "carers" (Aziz *et al.*, 2012). This may be due, for instance, to unclear boundaries between

routine family roles and the provision of care. Differences between available estimates are also linked to differences in survey questionnaire design and sampling criteria, as well as to the reliance upon proxy responses within household surveys such as the English Longitudinal Study of Ageing (ELSA) and the Family Resources Survey (FRS).

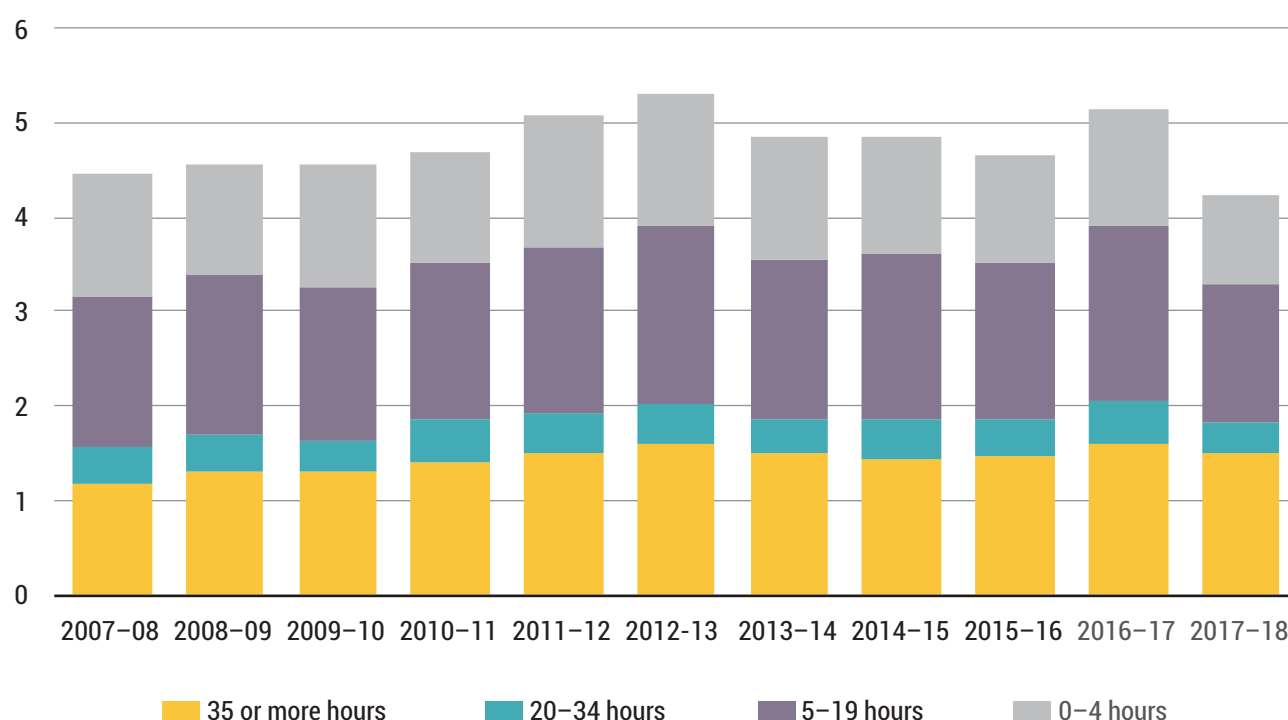
According to Census data, approximately 5.4 million people in England (just over 10% of the population) provided unpaid care in 2011 (Office for National Statistics, 2011); a relatively small increase of 0.18 percentage points relative to 2001. Between Census periods, however, substantial differences are evident in the characteristics of carers and intensity of care provided, with a noticeable fall in the proportion of working-age adults providing informal care in 2011 relative to 2001, offset by a substantial increase in rates of caregiving among older people; the fastest growth in provision being among spousal carers. Overall, the increase in the proportion of carers providing intensive support of 50 or more

hours per week (accounting for 21% of carers in 2001 and 23% in 2011) suggests a sizeable increase in the total amount of care provided between 2001 and 2011, the period preceding the implementation of the Care Act.

Though more prone to sampling bias, household surveys provide more frequent estimates of prevalence and intensity of unpaid care, covering the years immediately before and after the Care Act implementation. Family Resources Survey (FRS) data from 2007/8 to 2017/18 (Figure 1) suggest a steady increase in numbers of carers providing 35 or more hours of care per week from 2007/8 (equivalent to an estimated 1.2 million carers at the UK level) to 2012/13 (1.6 million carers), with numbers providing the most intensive levels relatively unchanged to 2017/18. By contrast, estimates of numbers providing lower levels of care (up to 19 hours per week) show a more volatile pattern, a finding that may be partially explained by the difficulty of measurement of low levels of caregiving activity (Evans *et al.*, 2012).

Figure 1: Estimated numbers of carers in the UK by intensity of provision, 2007/8 to 2017/18

Numbers of informal carers (millions)



Data Sources: Family Resources Survey, 2006/7 to 2017/18.

Overall, the national (UK) evidence above suggests that the numbers of adults providing intensive levels of unpaid care – potentially more likely to require local authority support – in the period 2012 to 2017 (pre and post-Care Act implementation) are broadly comparable, with perhaps a slight increase in numbers post 2015.

### 3.2.3 Carer assessments

As indicated in Figure 2, the numbers of carer assessments in England have declined steadily since 2009/10, falling from approximately 450,000 in 2009/10 to just over 350,000 per year in 2017/18. In 2014/15 (immediately prior to the Care Act), 297,000 joint or separate carer assessments were undertaken; numbers of assessments in the year following implementation had decreased by 14% to 256,000, falling to 240,000 assessments in 2016/17.

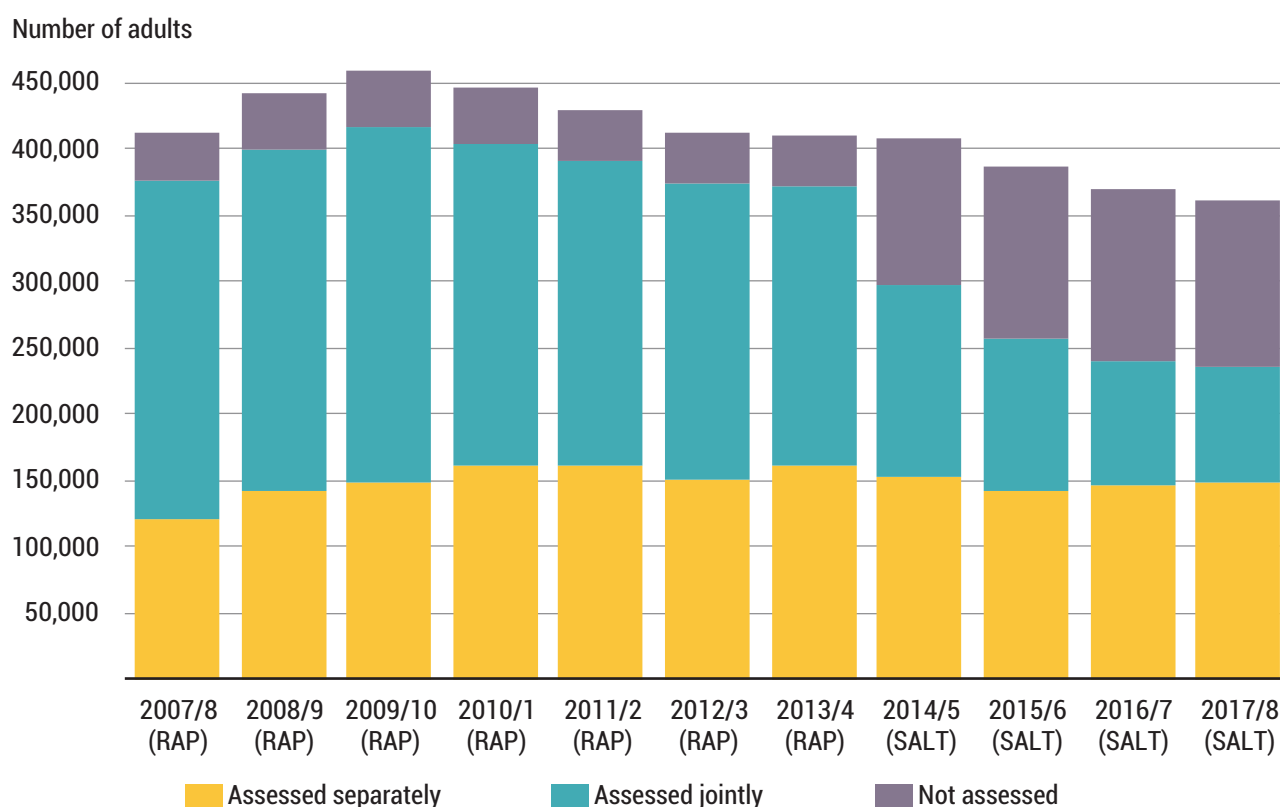
The multivariate regression analysis of levels of care assessments locally (see

Table 1) indicated that the numbers of carer assessments were significantly higher:

- In authorities with more carers (as proxied by the numbers of carers receiving the social security benefit the Carers' Allowance and the proportion of adults aged 65+ who are married or in a civil partnership)
- In authorities with greater social care need, as proxied by the proportion of people aged 85+ in the population and the proportion receiving Attendance Allowance
- In areas which, controlling for other factors, provide social care support to a greater proportion of their population.

Surprisingly, variations in carer assessments were not significantly associated to local authority social care expenditure levels, and bigger authorities (in terms of their population size) were found to carry out fewer assessments, controlling for other factors.

Figure 2. Numbers of carer assessments in England by assessment type (adults aged 18 and above), 2007/8 to 2017/18



In terms of the effect of the introduction of the Care Act on numbers of assessments, the multivariate regression confirmed the picture in Figure 2, and found that post implementation years were associated with significant reductions in standardised rates of assessments relative to the pre-implementation period. This finding is particularly striking given that the Care Act and associated increased local awareness-raising activities were expected to lead to significant increases in the numbers of assessments.

### 3.2.4 Service provision for carers

Aggregate time trends in service provision for carers mirror closely the patterns described above for carer assessments, with significant declines in the numbers of carers receiving support (services) from the period 2009/10 onwards (see Figure 3). This decline does not seem to have been affected by the implementation of the Care Act.

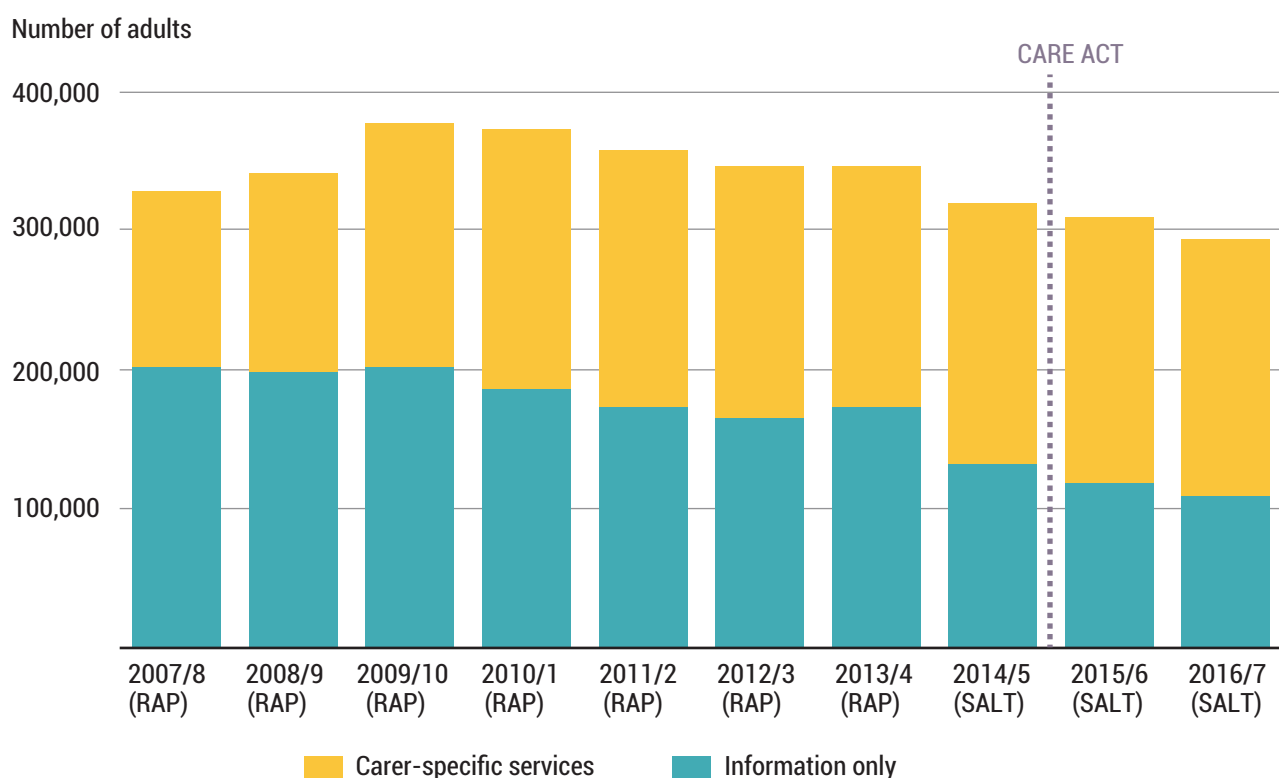
In addition, the years leading up to and following implementation of the Act are associated with an increased focus of

support on the provision of information only, as opposed to the provision of care specific services such as direct payments, personal budgets, or commissioned support.

Our multivariate regression analysis of trends in service provision for carers identified almost identical effects to those found by the modelling of carer assessments (see Table 1). Reassuringly, levels of service provision increased in authorities with higher numbers of carers, greater social care needs, and in authorities that provided social care support to a greater proportion of their population, controlling for other factors. However, levels of carers' service provision (information and advice or carer-specific services) did not seem to be associated with local net total social care expenditure.

Controlling for local characteristics does not seem to change the impact of the Care Act on levels of service provision observed in Figure 3: the years post-Care Act in the analysis are found to be associated with statistically significant lower levels of provision of carer support.

Figure 3: Numbers of carers' services and information provided in England, 2007/8 to 2016/17



### 3.2.5 Carer-related service expenditure

Expenditure on carer-specific services in the year following the Care Act saw the greatest proportional reduction (14%) across all client groups. Whereas overall social care expenditure increased by 3% in cash terms (1% in real terms) from 2015/16 to 2016/17, overall carer service expenditure decreased to £166 million – a fall of nearly 6% relative to 2015/16.

The multivariate regression analysis identified few local characteristics significantly correlated with differences in local levels of carers' service expenditure. Overall, the model examining carer expenditure achieved a much lower predictive power than the models examining assessments and levels of service provision, partly a reflection of the smaller number of years available for our analysis. Post-Care Act implementation years were again associated with statistically significant reductions in levels of expenditure on carer support (see Table 1).

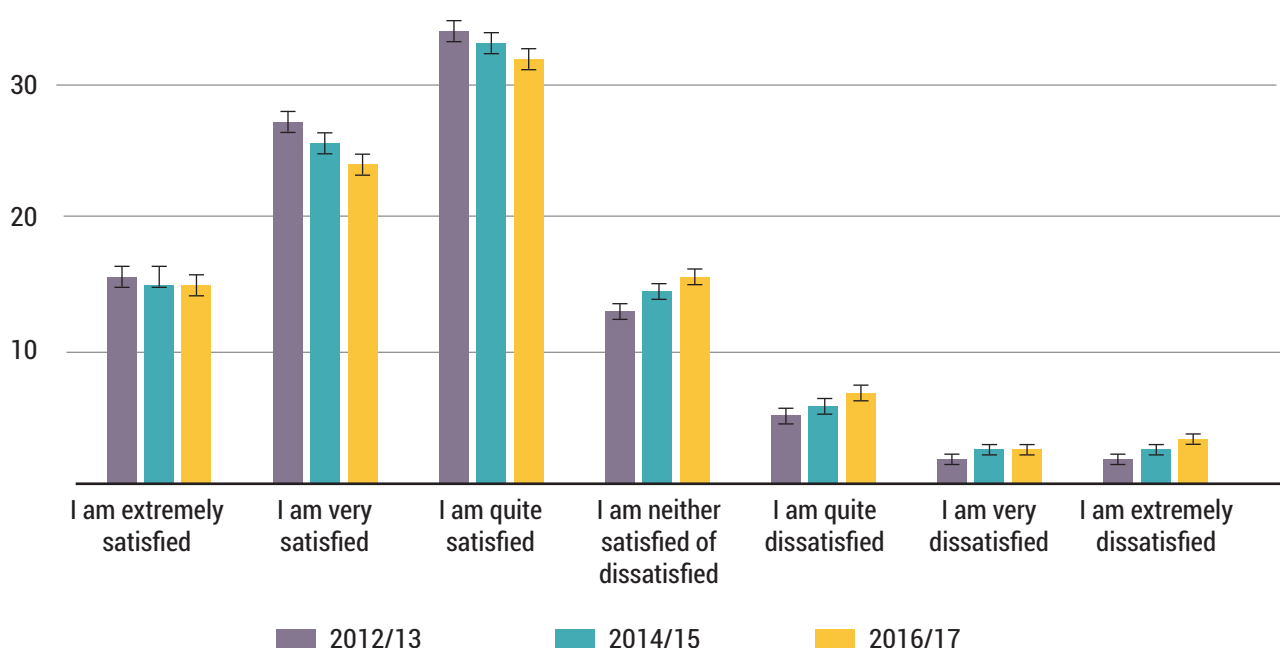
### 3.2.6 Characteristics and outcomes of supported carers

The individual level data from the Survey of Adult Carers in England (SACE) can be used to assess changes in the characteristics of carers receiving ongoing support from the local authority and in the support they receive. Our analysis of the 2012/13, 2014/15 and 2016/17 waves of the Survey of Adult Carers in England (SACE) found:

- A statistically significant reduction in the proportion of carers providing low levels of support post-Care Act. This suggests that ongoing support packages for carers have become increasingly concentrated on those carers providing the most intensive levels of care, in spite of the relaxation of the previous (pre-Care Act) restriction of statutory support to carers providing 'a substantial amount of care on a regular basis'.
- A significant increase post-Care Act in the proportion of carers that had not received information or advice in the previous 12 months.
- A small but significant reduction in the proportion of carers satisfied with local authority support post-Care Act (see Figure 4).

**Figure 4: Carer satisfaction with support received**

Proportion of respondents where service is provided (%)



Source: Personal Social Services Survey of Adult Carers in England: Time Series 2012–13 to 2016–17.

We carried out multivariate regression analyses of the levels of carer satisfaction with services (see Table 2). A limitation of this indicator is the fact that the carer's satisfaction measure relates to both the support they receive and the support received by the 'cared-for' person, if supported. It is therefore difficult to interpret the extent to which satisfaction levels reflect the impact of the specific carers support services received or the impact on the carer of the type and intensity of support package received by

the person they look after. We identified greater levels of satisfaction amongst older carers, non-working carers, carers supporting care recipients aged 65 or above and carers looking after someone receiving home care, meals, equipment or care home services. Controlling for differences in the characteristics of caregivers, care recipients and the intensity of unpaid care provided, these reductions in carer-elicited satisfaction post-Care Act remained statistically significant.

**Table 2: Factors associated with carer satisfaction during the previous 12 months**

	Coefficient	Significance level
Carer is aged 65+	0.135	***
Carer is in employment	-0.093	***
Intensity of unpaid care support	-0.025	***
Recipient is aged 65+	0.038	***
Recipient has used home care (past 12 months)	0.044	***
Recipient has received meals at homes service (past 12 months)	0.045	**
Recipient has used equipment (past 12 months)	0.173	***
Recipient has used information/advice (past 12 months)	0.230	***
Recipient has used support group (past 12 months)	0.056	***
Recipient has used employment support (past 12 months)	0.333	***
Year: 2014/15 (Care Act implementation)	-0.034	***
Year: 2016/17 (post Care Act implementation)	-0.115	***
Pseudo R <sup>2</sup>	0.04	

Note: \*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.001

### 3.2.7 Policy implications

Initial expectations were for the 2014 Care Act to lead to substantial increases in the numbers of carers assessed for (and potentially receiving) public support (Department of Health, 2014; Manthorpe *et al.*, 2019). According to a survey of local authorities conducted a year after implementation (LGA 2016), 59% of responding authorities felt that the Act had led to an increase in the number of carer assessments carried out (only 22% reported that volumes had decreased; the remaining 19% being unsure or suggesting

no substantive change). It is surprising, therefore, that published data suggest a decrease in the number of carers receiving assessments or support from local authorities in the years following the Act.

A number of factors may provide some explanation for these trends. It is important to consider levels of carer support in the context of overall expenditure on adult social care. Budgetary pressures faced by local authorities have led to real term decreases in expenditure since 2010/11, in spite of social care budgets being relatively protected. The capacity of local authorities

to meet policy ambitions with regard to carers has therefore been mediated by budgetary constraints as well as constant demographic pressures. It is also important to note, however, that the social care precept led to some recovery in overall social care budgets from 2016/17 but expenditure specific to carers continued to decline in the same year.

Personal accounts suggest that carers' knowledge of the services available to them is influenced more heavily by word of mouth than formal policy communications, possibly leading to a 'slow-burn' effect of policy changes rather than an immediate uplift in numbers coming forward for assessment (Department of Health, 2014). And so, it is possible that the overall effect of the changes brought about by the Care Act have not yet been felt fully. That said, modelling carried out for the initial Impact Assessment assumed that additional numbers of carers assessed would reach a steady state by 2017/18 (Department of Health, 2014).

Another important consideration is the fact that figures published in activity and expenditure returns may not comprehensively reflect the volumes of support provided. As identified in the process evaluation, a common response across authorities to the expected increase in the volume of carers approaching local authorities for support was to shift local authority in-house carers' activity to carer organisations in the voluntary sector. This voluntary sector led carer activity is difficult to quantify. Specifically, assessments or services that are publicly funded but provided by external organisations are not necessarily captured by existing local reporting mechanisms (Carers Trust, 2016; Health and Social Care Information Centre, 2017). If the prevalence of such arrangements is increasing, therefore, local authority return data may not provide a

reliable reflection of overall levels of support. This might explain how, despite the large apparent decrease in carer-related expenditure in 2015/16, LGA survey responses at the end of the same year (LGA, 2016) suggested that 61% authorities felt the costs of meeting carer needs had increased in line with or above expectations, and that 66% of suggested costs of additional carers' services were greater than or in keeping with expected levels.

In terms of the trends in assessments, it is also likely that total volumes of carer assessments in the official statistics underestimate the impact of the Act on numbers of new carers approaching local authorities for assessment. The proportions of carers in receipt of information or support that were recorded as having received an assessment or review during the financial year fell from 80% in 2014/15 (immediately prior to the Care Act) to 70% the following year, suggesting that local authorities may have focused resources more heavily on undertaking new assessments rather than providing reviews for those already in receipt of support.

Our analyses show that levels of public support for carers vary substantially between local authorities, and that this variation responds at least in part to differences in local needs and socio-economic characteristics. The divergence of time trends at the local level suggests that the overall impact of the Care Act has not been uniform across authorities. Overall, however, the provision of services and expenditure on support appear to have decreased over the two years following implementation of the Care Act to an extent that cannot be accounted for by differences in underlying population characteristics, or by limitations in the data available for analysis.

### **3.3 REVIEW OF LOCAL AUTHORITY WEBSITES ACROSS ENGLAND**

#### **3.3.1 Context**

The introduction of the Care Act placed new responsibilities on local authorities around their provision of information and advice relating to care and support, a duty which covered both support for the person in need of care and support and the responsibility to recognise and respond to

carers' specific requirements for information and advice, and, where relevant, to provide direct carer support.

Given the high proportion of carers reported to use the internet as a source of information (Carers UK, 2019; Tinder

Foundation, 2015), the study aimed to investigate the extent and nature of the information provided to carers by local authorities through their websites. Key aims were to:

- assess whether this information helped increase carer awareness locally and, in particular, helped people undertaking caring roles but not self-identifying as a carer to understand more about their situation and eligibility for support;
- provided a description of the legal responsibilities of the local authority that would be helpful for carers; and
- whether it described clearly and usefully the availability and charging arrangements for the services and support that might be accessed through the local authorities or through care organisations commissioned by local authorities to support carers.

We were also interested in whether the websites provided any information on response times, given that a Carers UK survey had earlier reported that carers were facing long waiting times for an assessment (Silman, 2016).

An audit of local authority websites undertaken in 2016 had highlighted the existence of conflicting information for older carers across the local authority websites and the over reliance on links to external websites, such as those provided by carers' organisations or the NHS (Lloyd and Jessiman, 2017). Our analyses built on this earlier work by Lloyd and Jessiman, which provides a useful comparison point to judge trends in the development of information and advice for carers since the introduction of the Care Act.

### 3.3.2 Methods

The website audit was treated as a 'mystery shopping' exercise, judging the websites as if the researchers were carers looking for information about how the local authority might support them (Wilson, 1998). We reviewed local authority websites including noting whether the local authority explained whether it undertook assessments in house or had outsourced the assessment process to an organisation they had commissioned to provide carer assessments on their behalf. A pro-forma for data collection was developed and

piloted, and in February 2019 a total of 79 websites, half of the local councils with adult social services responsibilities in England (CASSRs) were reviewed (the pro-forma is illustrated in Appendix 1). A random number generator was used to select the websites so although the final sample is not stratified by geography or population size, a sample of 50 per cent is unlikely to contain serious systematic biases.. The results were entered into an IBM SPSS Statistics data file. As a separate exercise, described below, we also reviewed a sample of websites of organisations which the local authority had commissioned to provide information, advice and support to carers on their behalf.

The survey collected evidence about whether the website included information on:

- the legal framework for supporting carers, including definitions of what was meant by the term 'carer';
- descriptions of needs eligibility criteria and systems for requesting an assessment;
- types of services available locally to support carers;
- links to other local and national organisations supporting carers;
- details of support services for those who have ceased to care;
- an explanation of how services are commissioned and information about any local strategy for carers;
- alternative ways of contacting the local authority for support as a carer (e.g. a dedicated telephone number).

A rating of 'user friendliness' in terms of appearance, lack of jargon, and so on was also developed for each of the websites surveyed which recorded ratings of the website's appearance in terms of visual appeal, comprehensiveness of information provided and quality (for example, functioning links to other websites).

Results were mainly recorded as dichotomous yes/no variables, in which 'yes' meant that the website included a clear answer to the question, for example, website refers to emergency support (e.g. "carers' cards").

### 3.3.3 Findings

The key findings of our survey of local authority and carer organisation websites included:

- Four fifths (n=66) of the websites examined included a definition of a "carer". The most popular definition used was the harmonised definition used across the NHS and by the Carers' Trust which is that 'a carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid' (NHS England, n.d.)
- Just over half of the websites examined (n=46) referred to the Care Act 2014. A similar proportion referred explicitly to carers' rights to an assessment (n=44).
- Just over a quarter of the websites surveyed (n=22) appeared to make no reference to carers' eligibility to receive services.
- Approximately two-fifths (n=33) of websites referred to support for carers of people who funded their own care. This potentially means that some carers of people who are self-funding may fail to recognise that they have a right to an assessment and possibly some services for carers, particularly their right to universal services, such as information.
- Almost all surveyed websites (n=73) referred to a carer assessment. Just under half provided a working link to a carer self-assessment tool.
- Almost three-quarters (n=56) of examined sites described the process for getting a carer assessment and explained what was involved in the assessment itself. However, less than two-thirds (n=48) explained who would be responsible for the assessment, including for instance, whether the assessment would be undertaken in house or contracted out.
- Only two websites surveyed included information on how much time carers might expect to wait before being assessed.
- Information and advice services were mentioned as services provided to carers on almost every website surveyed and it

appeared to be standard practice to refer carers to other sources of support available nationally and locally.

- There were fewer references to personal budgets for carers (n=45) or assistive technology (n=30).
- Just over a tenth (n=9) of the websites surveyed lacked information about additional ways to contact the local authority for more information about support for carers, such as by telephone.
- In terms of their comprehensiveness, only a third of the websites (n=24) were rated by the research team as "above average" based on the criteria agreed by the research team. Future work could explore if local authorities themselves audit their own websites using technical tools to measure their effectiveness. This is different from the data collection that could be undertaken by local authorities themselves, such as Search Engine Optimisation (SEO) scores (Operation Technology, 2020).

### 3.3.4 Potential impact

The researchers held a meeting civil servants from the Department for Work and Pensions as part of its 'Digital Discovery' project carried out in collaboration with the Department of Health and Social Care (DHSC) and the Cabinet Office to help improve web-based information for working age carers. They also attended two workshops for practitioners, carers, and local policymakers held as part of the Digital Discovery Project. They also worked in conjunction with researchers at the University of Bristol on a joint presentation of web audits before/after the Care Act at the British Society of Gerontology. Once the coronavirus emergency is over, we will discuss the value of such a checklist of developing a checklist for what information to include for carers on local authority websites with the Association of Directors of Adult Social Services.

### 3.3.5 Policy implications

Five years following its implementation, by 2019 almost all the websites reviewed had been updated to ensure that they were compliant with the 2014 Care Act. This represented an improvement as when we piloted the data form in 2017 we had identified some websites that still referred

to previous legal frameworks (e.g. quoting the Fair Access to Care eligibility regulations). However, there were still websites that appeared not to provide enough essential information to empower carers to receive appropriate support from their local authority or to access universal services provided through other organisations (e.g. the NHS and/or the voluntary sector).

Another striking feature of the websites reviewed was the significant variability in the content and organisation of the online information on carer support. Such variability does not seem to be justified on the grounds of the tailoring of the information provided to local care systems and is likely to be leading to differences in access to statutory support for carers across England.

Our evidence suggests, however, an improvement through time in the availability of information for carers. Relative to the results of the Lloyd *et al.* (2017) audit of local websites, we have found noticeable improvements regarding the availability of information about support/services, in particular covering universal services, safeguarding, as well as

the provision of external links to other sources of support. In fact, relative to the situation in 2016, we observed a marked increase in the proportion of local authorities referring to external websites for specific support and services, with many local authority websites directing carers to the local Carers Centre as the first point of contact.

In this regard, some local authorities appear to rely fully on these organisations to discharge their responsibilities towards carers associated with the 2014 Care Act. This reliance on external organisations can make it more difficult for carers to access the information they need, with an expectation that they should find and collate information from a range of sources rather than finding all the information directly from their local authority.

Although we should not assume that local websites reflect perfectly the range of services that might be available following an assessment of carers' needs, based on the information in local authority websites it appears that important carer support/services such as direct payments and personal budgets for carers are not publicised in many local authorities.

### **3.4 IN-DEPTH ANALYSIS OF INFORMATION SYSTEMS IN FOUR LOCAL AUTHORITIES**

In order to complement the quantitative information collected about the 79 local authority websites described above, we conducted an in-depth review of online and local policy information about carers' services in four case study local authorities in England. The aim was to gain a deeper understanding of how local areas implement Care Act obligations in respect of the provision of information for carers.

#### **3.4.1 Methods**

The four local authorities were selected to capture different types of local authority and local geographic profiles. They included a metropolitan council in the West Midlands (% of population 65+ = 14%), a non-metropolitan county in the Southeast (% of population 65+ = 20%), a metropolitan borough in the North-East of England (% of population 65+ = 18%) and non-metropolitan county in the South (% of population 65+ = 16%). In comparison, 18% of the population in England is aged 65 or

over.

The first step of this phase of the study involved searching the four local authority websites for specific pages with information on/for carers (of adults). The identified information regarding processes for carer identification, assessment, signposting, support and cross-sector collaborations collected from these 'carer pages' was recorded on an Excel spreadsheet. Identified mentions of the Care Act's new requirements in relation to carers' rights were also recorded. Next, in order to identify carers' services provided by independent (commercial and not-for-profit) providers, each local authority homepage was searched for an online service directory or similar, as well as information about whether the services mentioned were classified by ownership or governance. The review collected data about the types of services carers were told are available locally and – where possible – evidence about the specific agency

providing such services, directly or indirectly commissioned. In order to learn more about the specific relationships between the local authority and other care organisations in these case study sites, the local authority homepages were searched for documents outlining their commitments to carers, including any local carers' strategy, health and wellbeing strategy, joint strategic needs assessment, contracts and other financial reports. To identify which local NHS organisations were potentially providing carers' services or information, the search term "[local authority name] NHS" was put into the Google search engine. Pages maintained by local CCGs, NHS Trusts (Hospitals and secondary care services) were searched in the same way as the local authority pages including searching for relevant material around strategic planning and partnerships in carers' services. We also identified relevant links and online documentation that linked to voluntary sector local carers' organisations. The homepages and online documents of other voluntary organisations with a presence in the localities that mainly focus on specific target groups (e.g. Alzheimer's Society, Age UK, Mencap) but are also known to provide support to carers were also reviewed.

### 3.4.2 Key Findings

The key findings from the in-depth analysis of local information systems included:

- Authorities appear to be meeting their responsibilities towards carers in part. While useful information was generally available, our study revealed important variability in website content (in line with the findings from the survey of local websites noted above) as well as in the objectives that seem to be associated with local authority online information provision for carers. In particular, there seems to be a degree of confusion as to whether local information systems should concentrate on providing direct "practical" information regarding different types of services, their availability, and the steps necessary to commission such services, or whether their main purpose should be to act as a conduit to other organisations and to signpost carers to other sources of support available locally. On the whole, the evidence collected from the audit of local authority websites and from the in-

depth analysis of information systems suggests that the online systems of local authorities with generic local carer organisations concentrate on referring carers on to those organisations. The four sampled local authorities in the in-depth analysis provided explicit information on carers' rights and made reference to the Care Act. They generally offered relevant links to local organisations, mostly not-for-profit or voluntary groups. However, mention of national resources for carers varied, without apparent clear/coherent justification for their inclusion or exclusion.

- The quality of information was generally good in terms of its accessibility (language, layout, easy links up-to-date material) but with some notable exceptions. For example, not all the links provided on local websites worked or were up-to-date, and some of the pages were hard to navigate.
- Information about carers' organisations did not always make it clear whether these were the main providers of carer support in the local authority or whether a variety of voluntary groups provided specialist support for carers with interests in specific conditions, e.g. learning disabilities, dementia or autism.
- The NHS role in supporting carers was not easy to identify, and local authority websites often made reference to secondary NHS services rather than primary care – without noting referral criteria.
- Overall, there was little clarity about statutory (NHS and local authority) sector partnerships or commissioning arrangements. While detailed local governance and financial arrangements may not matter to carers, there was little portrayal of joined up provision or explicit mentions of relevant NHS services, and access to such services was not often explained. This could force carers to use separate channels in order to access support from the two sectors, without a clear understanding of the responsibilities of social care and the NHS, and with the associated risk of lack of coordination in the help provided.
- Partnerships with the private sector were not evident on the websites, with some minor exceptions.

### 3.5 UNDERSTANDING LOCAL POLICIES AND PROCESSES FOR SUPPORTING CARERS: PROCESS EVALUATION

The study carried out a process evaluation in four sites to gain an in-depth understanding of the policies and processes involved in supporting carers, including the approaches and practices taken in case-finding, needs assessment, and care planning. The process evaluation helped us to understand "how" and "why" different decisions about carer support were taken in the different areas surveyed. An important specific objective of the process evaluation was to establish the extent to which local policies and support systems had been affected by the implementation of the 2014 Care Act in 2015 and subsequently.

#### 3.5.1 Methods

The authorities participating in the process evaluation included a metropolitan borough, a non-metropolitan county and

two London boroughs. Although no overall representativeness can be claimed of the sample of authorities in the study given their limited number, they were chosen to reflect a cross-section of socio-economic characteristics; as well as varying in type, they differed in size, location, population mix, and policy approach to carers.

In-depth, semi-structured face-to-face interviews were conducted with 17 key informants in the case study sites over 2017–2018. The interviews in each site covered individuals involved in carers' assessment (care managers, first contact team members), policy representatives, head of services, commissioners as well as representatives from voluntary sector organisations commissioned by the local authorities to provide carers' services. Table 3 summarises the characteristics of the participants in the interviews.

**Table 3: Local authority case study sites' and informants' characteristics**

Local authority type	Informants' characteristics (R = respondent)
LOCAL AUTHORITY 1	R1 Carers Lead (social worker)
West Midlands Metropolitan borough	R2 Performance manager
	R3 Carers assessment team leader
	R4 Local Voluntary Organisation representatives (CEO and deputy CEO)
	R5 Local Voluntary Organisation first contact/assessment practitioners (x4)
LOCAL AUTHORITY 2	R6 Commissioning manager
Non-metropolitan county in South England	R7 Carer practitioner (social worker)
	R8 Front access manager (social worker)
	R9 Local Voluntary Organisation representatives (Chief Executive, Manager)
	R10 Data expert
	R11 NHS CCG representative
LOCAL AUTHORITY 3	R12 Business analysts (x3)
London borough (inner)	R13 Commissioners (joint commissioning)
	Commissioning lead (social worker)
	Service development officer (social worker)
	Strategic commissioner
	R14 Local Voluntary Organisation Head of Service
	R15 Head of Service, including carers assessments (social worker)
	R16 Head of Service, including carers assessments (social worker)
	R17 Front line practitioner (social worker)

We collected information about: local goals associated with supporting carers; intended outcomes; local strategies to assess the needs of, and support of carers; services provided to carers; coordination of efforts between the local authorities and other agencies in the design, delivery and assessment of services and if/how these changed following the Care Act. All interviews were recorded, transcribed verbatim and material was entered into qualitative data management software: NVivo 11 (QSR International, 2015). Thematic analysis was used to organise data systematically by focusing on identification and reporting of patterns and themes across the whole dataset to interpret the interview material (Fereday and Muir-Cochrane, 2006). In addition, we collected a wide range of policy and process documentary evidence, which was analysed in parallel with the evidence collected from the interviews.

### 3.5.2 Conceptual framework

Our analysis of the carer support models in the post-Care Act 2014 era in the local authorities in the study drew on Twigg's (1989) and Twigg and Atkin's (1994) theoretical framework. This framework helps explore whether and how the statutory care system engages with carers, and postulates that this relationship can be characterised as one (or a combination) of four types:

- Carers as resources: available and free source of care, interventions to support carers aim at ensuring that they retain the ability to provide unpaid care and potential conflicts of interest between the carer and cared-for person tend to be ignored.
- Carers as co-workers: complementing the activities of formal services. Formal services aim to work alongside carers, and to coordinate and complement each other's activity to ensure the continuity of care but also in terms of the quality of care provided.
- Carers as co-clients: with needs of their own to be supported. Carers' needs and their wellbeing are important outcomes per se, even if they conflict with the needs of persons cared for.
- Superseded carers: distinct from the person with care needs. This model

focuses on increasing independence of the carer and the cared for person so that both are freed from the relationship of dependence.

### 3.5.3 Key findings

The key findings from the process evaluation include:

- The Care Act appears to have legitimised the belief that carers need and deserve help in their own right and the study illustrated an increased local emphasis on identifying carers, supporting carers' health and wellbeing, as well as increasing emphasis on supporting carers' wellbeing alongside caring, including paid work.
- The evidence collected indicates that an important part of the local authorities' strategy for supporting carers was aimed at managing demand, and related to concerns around the sustainability of the care system with limited financial resources. Participants noted the existence in practice of tensions between the local authority objective to manage demand (and associated attempt to divert people away from statutory services) and a genuine desire to support carers' wellbeing, for instance through improving the availability of carer services in the voluntary sector.
- Prevention activities, such as building resilience, were reported to be closely allied to the goal of helping carers to continue in their caring roles. However, some respondents indicated that these policy aims sometimes masked strategies aimed at diverting people from using core social care services as a means of reducing pressure on local authority budgets.
- Key respondents reported that the collaboration with voluntary sector organisations increased following the Care Act implementation, particularly related to their involvement in the provision of low-level preventative services for carers. This was partly because authorities were expecting significant increases in demand following the implementation of the 2014 Care Act and its new eligibility criteria. Local authorities had anticipated a rise in demand for carer services which they thought they would not be able to meet,

therefore had sought to outsource some service provision or duties (including the carers' assessment function in one authority) to the voluntary sector.

- Collaboration between local authorities and NHSNHS partners (CCGs, GPs) was reported to be vital for the development of effective support for carers and revolved around jointly developed Carers' Strategies and projects. Reported challenges included disagreements around funding of services, discrepancies over the demarcation of responsibilities between health and social care agencies for jointly commissioned carers' services, and a limited number of referrals from GPs for carers' assessments in some areas. Notwithstanding these challenges, participants also highlighted examples of fruitful and successful joint work between the NHS and local authority sectors.
- All areas reported that the significant increases in demand for carers' assessments that had been expected prior to the implementation of the Act had not materialised; surprisingly to them the numbers of carers' assessments had either declined following the Care Act implementation or had remained similar in our sampled local authorities.
- Partly as a result of the expected rise in the numbers of carers approaching local authorities for support following the implementation of the carer eligibility criteria in the Act, some respondents from the voluntary sector involved in carers' assessments considered that their authorities had prioritised excessively the assessment of as many carers as possible. In their view, this could be detrimental as too many resources were being dedicated to completing carers' assessments, almost on a conveyor belt type basis as one participant noted, leaving little time and insufficient resources for providing support for carers. Replacement services (short breaks) appeared to have been most affected in this regard, with their availability limited in quantity and subject to means-testing of the person cared for as recipient of the support.
- The authorities in the study supported carers mainly through the provision of cash in the form of Direct Payments, as well as through non-statutory services delivered by the voluntary sector. Information and advice were mentioned as the most frequently provided services by local authorities, together with the funding of carer support groups.
- Many participants voiced their belief that providing information and advice services to carers can make a significant positive and direct impact on their wellbeing. This beneficial effect was linked to the therapeutic effect of the process of "listening" to carers' needs, the identification of possible solutions for the problems raised by carers, and the possibility of preventing situations from deteriorating. Conversely, it was highlighted that information and advice are not always enough, as many carers need more intensive services or support.
- As noted above, however, access to replacement services was seen to be very limited. Replacement care in the sampled authorities was being considered a service for the 'cared for' person only, rather than the carer. Such services were therefore unlikely to be available if the person with care needs was not eligible on the grounds of insufficient need. In addition, as a service for the cared-for person, replacement services were regularly subjected to the financial means-test, in contrast with other carer services, which meant that some carers did not benefit from replacement care due to its cost.
- Treating replacement care as a service for the person with care needs was reported to occasionally have led to conflicts between carers and the person they were supporting, because the latter may not always think it is necessary for their carer to have a break. Treating replacement care as a service for the person with care and support needs was also reported to have taken control away from carers and to have led to a disempowering effect on them.

### 3.5.4 Policy implications

Attention to carers' needs has been accentuated in recent years at policy level while carers' health and wellbeing became a key element in policy discussions. The Care Act 2014 and new eligibility criteria aimed to support carers in their own right,

irrespective of the eligibility of the person they care for. This policy framework links well with Twigg and Atkin's (1994) carers as co-clients model as it puts carers' needs at the centre of assessment and demands service responses which need to focus on beneficial outcomes for carers. Essential to this model is a broadening of attention from the priorities or circumstances of people with care and support needs to carers' needs and wishes. Our in-depth interviews suggest that the co-client frame of reference describes most accurately the nature of the relationship between statutory services and carers in the post 2014 Care Act period. The evidence gathered suggested increased local emphasis on supporting carers' health and wellbeing as well as increasing emphasis on supporting carers' wellbeing alongside caring, including paid work. The Care Act appears to have legitimised at service level the belief that carers need and deserve help in their own right.

Respite care was an important exemplar of services supporting carers in the co-client model according to Twigg and Atkin (1994) who considered respite to be clearly directed to carers as a recognition of the burden or difficulty of care. Respite or replacement care could also support carers and implement the Care Act's ambitions to help carers have a life of their own alongside caring and to have breaks from their caring responsibilities. Although respite was provided or funded by local authorities in our study, it was often considered as a service for people for whom carers provide support, thus subject to their needs and financial assessment. The potential conflict of interests between the needs of carers and the people they support has long been recognised in the literature (Lloyd, 2000; Moriarty, 2012; Williams and Robinson, 2001), and the current local approaches to replacement care appear to risk disempowering carers, contrary to the Care Act goals. Even prior to Care Act implementation, practitioners often found it challenging to distinguish between carers' services and services for the person being supported (Mitchell *et al.*, 2015). As our data illustrate, the demarcation between carers' services and services for the person with needs continues to be blurred despite the Care Act's goal to recognise and provide support for carers in their own right. Moreover, the

redefinition of replacement care from a service that used to be considered for carers to that for the care recipient has undermined carers' support in some local areas post-Care Act, making carers' receipt of the service dependent on the eligibility and approval of the person with needs for care and support. Rather than initiating a process of separation between the needs of carers and people with disabilities, potential conflicts of interest between carers and people being supported appeared to have been overlooked in the re-conceptualisation of replacement care entrenching the resource model.

The carer as resource model was most clearly articulated in the local discussions around demand management. Most participants identified the importance of carers in keeping people with care needs away from the health and social care systems. The period following the Care Act implementation was characterised by declining net social care resources with the consequent need to cut services, particularly in less well-off areas (Hastings *et al.*, 2015). Consequently, carers were often seen as a resource with concerns about carers' welfare being often overridden by anxieties over the sustainability of the care systems (Twigg, 1989). Limiting services for carers has been a feature of carers' services for several years in England and, despite the Care Act's focus on supporting carers, some authorities still appear to protect resources by channelling prospective carers-clients to other services or organisations (Arksey, 2002). Although ensuring that carers continue to provide care was rarely the only or explicit reason for providing carers' support, the carers as resource framework appeared to be highly influential in rationalising support for carers which blurred the focus of policies and schemes.

Though respondents from both voluntary organisations and councils highlighted that carers were clients in their own right; LAs respondents, regardless of their role or professional background, appeared to be more concerned about the sustainability of the care system, thus also frequently emphasising carers as a resource. The emerging conflict between Care Act's emphasis on supporting carers in their own right, and a formal sector approach which treats them as resource, was often resolved

by accentuating carers' preferences which, as some participants in our study often believed, were not incompatible with the resource approach.

This analysis also suggests that, in practice, social care practitioners still encounter carers who appear to be unwilling to be recognised, and consequently are not supported by formal services as carers. To some extent this is predictable in a family orientated ideology – many individuals may feel that they are carrying out regular tasks as part of a family (Lowenstein and Daatland, 2006) while for others approaching social care services may be stigmatising in itself. Moreover, the use of the word 'carer' may be problematic, particularly for individuals unacquainted with the term (Heron, 1998). It is thus not sufficient to rely on carers to identify themselves (Guberman *et al.*, 2003) while factors such as attitudes of carers (and of the person they support) towards their caring role clearly can mediate local authorities' ability to respond to carers' needs (Twigg and Atkin, 1995).

Twigg and Atkin (1994, p.12) noted that formal care systems do not draw solely on any one model, rather 'agencies and service providers shift between the different frames of reference in response to the particularities of the situation'. The models which these authors constructed provide a framework for understanding how formal services interact with carers and we used them as a means for exploring local perspectives of such interactions post-Care Act. The findings indeed suggest that despite a clear Care Act emphasis on support for carers as clients in their own right, in practice and faced with the reality of financial constraints and concerns about the sustainability of the care system, local authority systems still approach carers at least partly as resource.

The Care Act seems to have made considerable progress in legitimising carers as co-clients and thus the care system and social care practitioners are increasingly emphasising meeting carers' needs and wellbeing as valued and desirable outcomes; however, in practice, resources render this more an aspiration than achievement.

### 3.6 CARERS' INTERVIEWS AND CARERS' SURVEY

The study took a mixed-methods longitudinal approach to explore the landscape of 'replacement care' services and other support received by carers pre- and post-Care Act and investigate any associations pre- and post- Care Act between service receipt and carers' employment outcomes. To achieve this, we built on two surveys of working-age carers carried out by members of the research team in 2013 and 2015 as part of the NIHR School for Social Care Research project 'Overcoming Barriers: Unpaid Care & Employment in England Longitudinal Study' (Brimblecombe *et al.*, 2018; Pickard *et al.*, 2018). As part of the current evaluation, we conducted a follow-up survey in 2017 and undertook quantitative analysis of the data from all three waves of the survey. The quantitative analysis of the survey data was combined with qualitative analysis of in-depth interviews with a sub- sample of carers who responded to the survey.

Our carers' survey and in-depth interviews therefore complimented the other strands

of analysis in the evaluation by providing a direct picture from carers of their perceptions regarding the support system post-Care Act. In particular, we sought to understand carers' views regarding access to different types of services (including replacement care) and on the ability of the post-Care Act social care system to support carers to achieve their own personal goals, and in particular their ability to combine employment with their caring role.

#### 3.6.1 Methods

**Survey:** The target population for the survey were adults living in England who were in paid employment in several targeted local and national government organisations at baseline and were providing unpaid care to a family member or friend. We aimed for a range of employment types and levels and a range of caring experiences, some of which changed over time. We targeted employers known to have relatively 'carer-friendly' working practices to enable us to

focus more on any (additional) role of services. Employers were identified with help from Employers for Carers ([www.employersforcarers.org/about-us/who-we-are](http://www.employersforcarers.org/about-us/who-we-are)), a membership forum for employers committed to 'carer-friendly' employment practices. Initially carers were identified through an online screening survey carried out in 2013. Carers identified in the initial survey who opted into the second stage of the study were sent a self-completion postal questionnaire in 2013. This included questions on socio-demographic characteristics, employment, provision of care, and service receipt. In 2015, respondents who had completed a questionnaire in 2013 were sent a follow-on self-completion questionnaire. In 2017 respondents who had completed questionnaires in 2013 and 2015 were sent a second follow-on questionnaire. Similar questions were asked at all three waves. The sample included only carers aged below State Pension age at follow-ons. The resultant sample of eligible carers who had completed the survey at all three waves was 157. Quantitative analyses combined descriptive statistics of the characteristics of the sample and service receipt at each timeframe. We then used regression models to compare employment outcomes for carers where the care-recipient received key services compared to where they did not.

**Interviews:** Additionally, we carried out 11 follow-up in-depth telephone interviews in 2017/18 with a sub-sample of respondents who had completed questionnaires in 2013, 2015, and 2017 and taken part in an interview in 2015. The sample included different caring and employment situations. Interviews explored the associations between services and carers' employment in depth. Interviews were recorded and transcribed in full, with the permission of participants. Transcripts were coded using the qualitative data software package Nvivo into themes and patterns using thematic analysis.

### 3.6.2 Key findings

- The survey data illustrated a slight increase in the number of care hours provided over time by the carers in the three surveys and a larger increase in the proportion providing personal care. Increasing proportions of carers reported

that their health was fair, bad, or very bad over time.

- In marked contrast to the previous finding that receipt of services by the person with care needs ('replacement care') in 2013 was associated with carers subsequently being more likely to remain in paid employment, we did not observe a significant association between service receipt in 2015 and carers' subsequent employment. Interview data indicate that this is likely to be because services did not increase in response to increasing care and carer needs and that the level of support was not sufficient to enable carers to remain in employment.
- One reason for service receipt not keeping pace with need may be the low rates of assessments and review assessments for the carer and the person with care needs reported in both survey and interviews.
- Interview data suggested that 'replacement care' services have the capacity to support carers' employment in the right circumstances, and when provided with sufficient intensity.
- We found that many carers were 'struggling on' with a pattern of some services received, some adjustments to their working life, and some negative impact on their health. This often ultimately resulted in carers leaving employment because they had exhausted flexible working options and/or the combination of their health getting worse and increasing caring responsibilities meant they were unable to continue working.
- Both interview and survey data indicate that a carer's ill health (in combination with caring responsibilities) contributed to carers leaving paid employment. Health appeared to be more of a factor in 2017 than 2015 survey. This could be because of carers becoming older and/or as a result of increasing and longer-term caring responsibilities.

### 3.6.3 Policy implications

As noted above, the 2014 Care Act was characterised by high expectations and the ambition to support working carers. It represented a step forward in carers' rights. However, its enactment coincided with cuts

to local authority budgets which hampered their ability to implement many of those new rights with respect to carers' assessments and carers' support (Carers Trust, 2016; Lloyd and Jessiman, 2017). Our study shows how it may have also hampered them in relation to 'replacement care', in particular to 'replacement care' responding to changing/increasing care needs and carers' circumstances. This is important because needs in these situations are rarely static. One route to being responsive is through care-recipient and carer assessments and regular reviews, and the implementation of any resultant care and support plans. NICE guidelines for older people with social care needs and multiple long-term conditions recommend regular reviews and updates to care plans because long-term conditions can be progressive or changeable in themselves and importantly because 'people want to do different things with their lives at different times, and that the way that people's long-term conditions affect them can change over time' (National Institute for Health and Care Excellence, 2015). The Care Act 2014 is clear in its expectation of regular reviews of care and support, and support plans, initiated by local authorities and/or on 'reasonable' request from the person with support needs or the carer. In practice, long-wait times for assessments and 'fatigue with constant change' (Baxter *et al.*, 2011) can mitigate against this. Baxter and colleagues found that the process was facilitated by 'determination, energy, support from professionals and family, and the ability to challenge bureaucracy and seek information' (*ibid.*, p. 3). Not everyone has these resources.

Personalisation may be another route to enabling services and other support to be more responsive to changing needs. Personalisation of care was set out as a policy goal by the government in England in 2007 (HMG, 2007) and extended in the 2014 Care Act to the requirement that all eligible adult social care users should be offered a personal budget (PB). For some

people, personal budgets improve flexibility (National Audit Office, 2016; Stevens *et al.*, 2011), although they also need to be responsive to changing needs. As the recent National Audit Office report and others have said, achieving the aims of personalisation requires adequate funding and support (National Audit Office, 2016). Funding cuts have impacted on personalisation both through amount allocated and through reduced flexibility and choice resulting from, for example, the financial need by local authorities to keep some block contracts for homecare services (National Audit Office, 2016). The Carers Trust report on the Care Act implementation concluded that personalisation in support planning for carers had so far not fulfilled its promises (Carers Trust, 2016).

A flexible responsive approach to service provision is certainly important. However, early intervention is also needed. As our study shows, once the situation has deteriorated and carers have left employment, it is difficult to reverse that. Carers experience problems returning to work (Carmichael *et al.*, 2010; Van Houtven *et al.*, 2013), and their ill health exacerbates that. Early intervention and preventing or delaying the development of needs for support among carers were an associated part of the 2014 Care Act that may need revisiting.

While our study shows the importance of flexible working conditions, these were generally not enough on their own to prevent carers leaving employment, especially when care needs increased. Extending rights to flexible working is thus important but not sufficient on its own (Arksey and Glendinning, 2007; Bouget *et al.*, 2017). Adequate services for the person they care for and other support for carers are also needed to protect their employment. However, the availability of such good quality support for carers appears to be increasingly limited in recent years (Arksey and Glendinning, 2007; Bouget *et al.*, 2017).

## CONCLUSIONS:

### REALITY MEETS POLICY INTENTIONS – THE UNREALISED AMBITIONS FOR SUPPORTING CARERS OF THE 2014 CARE ACT

Nobody can doubt the significance given to carers by the 2014 Care Act legislators. As our analyses of the Parliamentary debates show, the Act was intended to mark a historic improvement in statutory support for carers by making their rights to assessments of their needs independent of the person they care for, introducing more transparent, nation-wide minimum eligibility-criteria, and imposing new responsibilities on local authorities around the provision of information and advice. As reflected in the government's Impact Assessments, the Act was expected to lead to substantial increases in the number of carers approaching local authorities for support, in the numbers of carer assessments and in the numbers of carers that would go on to receive services. It is worth noting, however, that whereas the Act sought to strengthen and clarify the relationship between the state, carers and people in need of support, the primary responsibility for looking after people with social care needs was always intended to remain with families. These expectations regarding the role of the family were reflected, for instance, in the praise given during the Parliamentary debates to individuals looking after their relatives.

Our process evaluation showed that local authority staff at all levels of the organisation welcomed the greater clarity about carers' rights in the Act and that they shared its aspirations to improve the provision of carer services. However, it also highlighted the widely held beliefs that, as a result of the reforms, many more carers would approach the local authority and that this potentially posed a significant challenge to the authority's finances.

In this sense, the Care Act provided a catalyst for increased collaboration, and many local authorities responded to the expected growth in service demand by developing new or strengthened

partnerships with their local carer organisations. In the authorities in the study, for instance, the local Carer Strategy was either led by the local carer organisation or co-produced in partnership with the local authority and other stakeholders, sometimes including NHS agencies. These partnerships led to a much greater involvement of the local voluntary sector in the organisation and delivery of carer support, and several carer organisations were given the lead responsibility for case finding and for carrying out carer assessments. We found less evidence of partnerships with the NHS.

At the same time, greater emphasis was placed on information and advice as the preferred means of support for carers (as opposed to the provision of ongoing replacement care or of Direct Payments). These changes were predicated on the grounds that information and advice would improve carers' wellbeing by empowering them to access local universal support services, but also out of a desire to divert growing demand for services away from the financially stretched adult services departments in local authorities. The shift towards information and advice as a 'service' was reinforced by changes in the social care charging arrangements, which redefined replacement care as a service for the person with care needs (and not for the carer) and thus restricted access by subjecting it to the user's social care means-test and needs eligibility criteria. Our interviews with local authority and voluntary sector professionals identified significant tensions involved in balancing, on the one hand, the objective of maximising carers' independence through increasing the provision of information and advice, and, on the other, the risk of undermining carers' wellbeing by reducing their access to practical and emotional support.

The value of direct support, in particular for carers looking after people with significant needs, was further highlighted in our carer interviews and in the evidence collected through our carers' survey. This evidence painted a picture, post-Care Act, of infrequent assessments and reviews, and of shortfalls in the availability of replacement care which impacted on carers' wellbeing and labour market outcomes. However, we also heard from professionals based in local carers' organisations about the potential therapeutic value for carers of the process involved in their needs assessment and the provision of information and advice. It would be important for a future evaluation to examine the impact on carers' wellbeing of different models of provision of information and advice, given the prominence of this type of support in the post- Care Act social care system.

Our quantitative analyses sought to understand the net effect of the changes brought about by the Act on local service patterns. They suggest that, contrary to ambitions and expectations, and consistent with the findings from the carers' survey and interviews, the Care Act did not lead to increases in statutory support for carers. The volume of carer assessments, the number of carers receiving support and levels of local authority gross expenditure on carers all continued to decrease post-Care Act, as did carer satisfaction with the support received. These results require careful interpretation, however, as they are unlikely to indicate that the Care Act led in itself to reductions in the availability of support for carers. Instead, they are most likely related to the fiscal environment during the period in which the Act was implemented, and in particular to reductions in local government budgets since 2009 (Harris *et al.*, n.d.). Similar reductions in expenditure and activity have been found over the same period in most other aspects of social care provision. It is also important to note that the limited coverage in the local authority returns of services provided through the voluntary sector means that it is difficult to paint a fully comprehensive picture of local

authority-funded support. This limitation is particularly important when examining carers' services due to the growing involvement (noted above) of local carer organisations in needs assessments and the provision of local authority-funded services.

In addition to increasing the amount of carer support, the Act aimed to reduce the extent of local variability in access to services through the introduction of clearer national minimum eligibility criteria. The limited explanatory power achieved by our multivariate regression models predicting local levels of carer support as a function of local characteristics suggests that significant variability remains. Our study also provides evidence of large variations in the nature and extent of information provided by local authorities through their websites and begs questions about the role of the internet within local authorities as the key form of public communications. Our findings suggest that there might be value in developing, in partnership with carer groups and accredited information and advice-providers, minimum standards covering information provision by local authority social care departments. The need for this may be increasing with possible changes in means-testing of social care, as argued by many of those campaigning for the reform of social care funding. If this is to happen then many more people may be seeking information and advice about finances and decision-making.

In summary, our evaluation suggests that the impact of the 2014 Care Act on carers in England could be described as a combination of conceptual achievements and practical challenges. The improved clarity about the roles and responsibilities of the state towards carers was notable and widely welcomed by social care stakeholders. However, the impact of strengthened carer rights appears to have been limited by the requirement for local authorities to keep within budget, and as a result these rights have not led to greater access to support for carers.

# KNOWLEDGE EXCHANGE AND DISSEMINATION

## 5.1 USER, CARER AND/OR PRACTITIONER INVOLVEMENT IN THE STUDY

The study set up an Advisory Group comprised of carers, researchers, service providers and practitioners, which met three times during the life of the study (March 2017, March 2018 and May 2019). Advisory Group members helped the study's researchers by considering aspects of research design, including commenting, for instance, on aspects of research such as the content of interview and survey questions. The Advisory Group also supported the researchers in interpreting the interim and final study findings of the project, and provided ideas and advice regarding our proposed knowledge exchange strategy.

In addition to the three face to face meetings, several Advisory Group members advised the project remotely (via email or by phone) throughout its life, for instance in relation to the progress of the analyses, the interpretation of study findings and the implementation of our engagement strategy with local stakeholders.

Two members of the study's Advisory Group are continuing to work with the study researchers, for instance as part of the Adult Social Care Policy Research Unit (ASCRU) Public and Patient Involvement and Engagement group. Another is assisting with our dissemination to social work communities.

## 5.2 KNOWLEDGE EXCHANGE METHODS APPROACHES IN THE PROJECT

Given that the purpose of the study was to inform the Department of Health and Social Care about the implications of the implementation of the Care Act 2014 for carers in England, many of the knowledge exchange activities undertaken by the research team have involved interaction with policy makers and analysts.

The research team held two meetings with policy leads and analysts in the Department of Health and Social Care (DHSC) and with the Department of Work and Pensions (DWP) to report and discuss the project's methodology and emerging research findings. Following these meetings, Nic Brimblecombe and Jo Moriarty engaged with DWP on its project on "Carers' Employment Digital Discovery", meeting with the team and represented the study in two stakeholders' workshops in 2018 and 2019.

The principal investigator, Jose Luis Fernandez, spoke to members of the Cabinet Office in July 2019 about the

project study and its findings, in the context of a review by the Economic and Domestic Affairs Secretariat (EDS) of strategies for supporting carers, as part of the Government's focus on social care.

The research team held feedback sessions with the individual local authorities taking part in the process evaluation of the study to report on findings in general and to report more in-depth on interim findings relating to the particular authority, and to get their input and views on the progress, design of the study and also their views on the interpretations of the findings. Jill Manthorpe was invited to speak at one site's social work conference to discuss emerging study findings on World Social Work Day in 2017 and has shared interim study findings with social workers undertaking continued professional development (CPD) training.

The research team held a final one-day joint feedback session with representatives of the local authorities, health care

agencies and voluntary sector organisations which took part in the process evaluation to discuss the project findings. In addition to “feeding back” the findings, the meeting aimed to engage with the project stakeholders to help with the interpretation and sense checking of the analysis findings. The session triggered an extremely useful discussion, which helped sense-validate and contextualise the study results. The discussion was recorded and analysed and helped draft the final version of this report around various aspects of study findings and its interpretations.

We also held several feedback sessions with individual local authorities that supported the evaluation to report on study findings in general and to report more in-

depth on interim findings from their authority and to get their input and views on the progress, design of the study and also their views on the interpretations of the findings.

A presentation summarising the results of the project was given in June 2019 as part of a workshop organised by the Department of Health and Social Care sharing the findings of the different strands of Care Act 2014 evaluations.

We used the study's background research to author a chapter in a textbook for social workers to explain the Care Act changes related to carers. This edited text was the first major text-book on the Care Act.

### **5.3 PUBLICATIONS LIST**

#### **5.3.1 Published papers and chapters**

Manthorpe, J., Fernandez, JL., Brimblecombe, N., Knapp, M., Snell, T. and Moriarty, J. (2019) Great expectations: ambitions for family carers in UK parliamentary debates on the Care Bill, *International Journal of Care and Caring* 3(3), <https://doi.org/10.1332/239788218X15411706089442>

Manthorpe J., Moriarty, J., Brimblecombe, N., Knapp, M., Snell, T. & Fernandez, JL. (2019) Chapter 5: Carers and the Care Act: promise and potential in *The Care Act 2014: Wellbeing in Practice* (eds Suzy Braye and Michael Preston-Shoot), London, Sage.

#### **5.3.1 Submitted papers**

Marczak, J., Fernandez, JL., Manthorpe, J., Brimblecombe, N., Moriarty, J., Knapp, M. and Snell, T. (submitted 2019). How have the Care Act 2014 ambitions to support carers translated into local practice? *Health and Social Care in the Community*, accepted subject to revisions.

#### **5.3.2 Planned publications/papers in preparation**

Damant, J., Manthorpe, J., Fernandez, JL., Moriarty, J. *et al.* Local online information for carers in England: what might be the impact on ‘care seeking’ behaviour? Paper to be submitted to *Working with Older People*.

Brimblecombe, N. *et al.* Carers Survey and Interviews. Paper to be submitted to *Journal of European Social Policy*.

Moriarty, J. *et al.* A duty to establish and maintain information and advice services: what carers can expect from council websites. Paper to be submitted to *Working with Older People*.

Snell, T. Fernandez, JL *et al* Carers and The Care Act 2014: policy intentions versus local patterns of support. Paper to be submitted to the *Journal of Social Policy*.

## 5.4 PRESENTATIONS BASED ON STUDY FINDINGS

The presentations based on the study findings throughout the life of the project included:

Meeting on 5th September 2018 with members in the Department of Health and Social Care and Department of Work and Pensions:

- Interacting with the system as a carer: evidence from the audit of LA websites, J. Moriarty
- Recent patterns in levels of support for carers: evidence from national statistics, T. Snell and Fernandez, JL.
- Perceptions of the system from carers, Brimblecombe, N
- The view from local stakeholders: evidence from local process evaluation, Marczak, J.

The research team held a feedback session with local authorities taking part in process evaluation on the 9th of April 2019 at the London School of Economics, where the following papers were presented reporting findings from the study:

- Secondary analysis of local authority data, Snell. T
- Process evaluation: Local stakeholders' views, Fernandez, JL
- Carers' survey and interviews, Brimblecombe, N
- Web audit of local authority websites, Moriarty, J.

In addition, the following presentations used evidence from the project:

- Moriarty, J. 2018a. Social care datasets, ethnicity, access and experience of services. Workshop – Embedding ethnicity and migration into health inequalities research. Sheffield, 4 June 2018.
- Moriarty, J. 2018b. Social care datasets, ethnicity, and access to services. Health Inequalities Research Network Conference 2018. London, 31 October 2018.
- Zhang, W. and Lloyd, L. 2018. information and guidance for unpaid family carers: reviews of local authority websites. British Society of Gerontology 48th Annual Conference. Liverpool, 12 July 2018.

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