

Title: The role of formal care services in supporting young people who provide unpaid care in England

Authors

Nicola Brimblecombe (corresponding author), Care Policy and Evaluation Centre, London School of Economics and Political Science n.s.brimblecombe@lse.ac.uk 0207 955 6376

Madeleine Stevens, Care Policy and Evaluation Centre, London School of Economics and Political Science

Derek King, Care Policy and Evaluation Centre, London School of Economics and Political Science

Martin Knapp, Care Policy and Evaluation Centre, London School of Economics and Political Science

Acknowledgements

The authors wish to thank the young people who gave their time to take part in this research and share their experiences with us. We also wish to thank the project advisory groups including the young adult carer advisory group, and our funder. This research was funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). The views expressed are those of the authors and not necessarily those of the funder or the Department of Health and Social Care, NIHR, or NHS.

The role of formal care services in supporting young people who provide unpaid care in England

Abstract

A large proportion of long-term care for people with disabilities and/or long-term health conditions is provided by unpaid carers, including young people, with potential impacts on their education, employment and health. Supporting carers is a focus of long-term care practice and policy in many countries. A key part of this support in England is through provision of services to the person with care needs (often called 'replacement' care). We aimed to explore the role of replacement care services in supporting young adult carers' health, education, and employment. We used a mixed-methods approach: self-completed questionnaires and in-depth follow-on interviews. We found ways in which services supported young adult carers but, contrary to previous research, receipt of services by the person with care needs was not associated with better reported carer outcomes in our survey. One key reason for this finding was that not enough services were received to meet care needs and alleviate unpaid caring to a level or type compatible with better outcomes. The wider economic and political context of our study, during fiscal austerity and cuts to social care budgets, and the particular circumstances of young adult carers may offer further explanations.

Introduction

Provision of long-term care is an important policy and societal concern in many countries worldwide.

Unpaid care makes up a large proportion of the care provided and received (Colombo *et al.*, 2011; World Health Organization, 2015). This includes care provided by children and young people.

However such provision of care by young adults, as by other unpaid carers, is associated with poorer mental health and wellbeing, and impacts on education, employment and social participation (Becker and Becker, 2008; National Union of Students, 2014; Authors, submitted). For young people, caring responsibilities can additionally cause difficulties with many of the usual transitions to adulthood such as entering further or higher education, employment, personal relationships and/or leaving home (Dearden and Becker, 2000; Becker and Becker, 2008).

Policy on young and young adult carers in England has emphasised that 'children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive' (2008 National Carers Strategy; HM Government, 2008, p123). Recent policy in England – the 2014 Care Act and the 2014 Children and Families Act - brought in important new rights for young people who provide unpaid care. Key among these were rights to an assessment of their needs. This assessment should include consideration of whether caring has an impact on a person's wellbeing, personal development, physical and mental health, and should consider their needs to participate

fully and fulfil their aspirations in education and employment (Care Act, 2014; Children and Families Act, 2014). Taking into account young and young adult carers' needs as well as those of the family member they care for is part of the requirement to take a 'whole family approach' (Care Act, 2014; ADASS, 2015).

A second key right brought in by the 2014 Care Act was that local authorities must consider the option of the young carers' needs for support being met by providing services to the person they care for, so-called 'replacement' care (Care Act, 2014). In addition, local authorities have a requirement to prevent future need, such as preventing a caring role having a negative impact on a carers' wellbeing. This prevention role can also be met by providing services to the person with care needs: 'a local authority should consider how supporting the adult with needs for care and support can prevent the young carer from undertaking excessive or inappropriate care and support responsibilities' (Care Act, 2014). Prevention of taking on caring responsibilities or mitigation through reducing caring responsibilities are two possible roles support for carers might play according to Purcal *et al.*'s (2012) framework.

The option to provide services for the person with support needs to also meet the needs of the young adult carer is important. Provision of care by young adults often stems from lack of suitable alternative provision for the person with support needs (Commission for Rural Communities, 2013). Young adult carers themselves identify the need for better support and services for the person they care for (Wayman *et al.*, 2016). Supporting young carers by improving support to the person they care for also takes into account the 'dual focus of caring' (Twigg, 1992): caring occurs in a relationship, and policy and practice should accommodate the needs and rights of carers and people with support needs. As has been noted previously (e.g. Olsen, 2000), a focus on services and support for the person with support needs can contribute to reconciling the rights and needs of unpaid carers and those of disabled and older people. Some researchers have long argued that the best way to stop inappropriate caring by children and young people, and indeed the best way to support young carers, is for the person they care for to receive adequate services and support (e.g. Keith and Morris, 1995).

Previous research has found that provision of services was associated with better outcomes for carers' employment (Geyer and Korfhage, 2015; Haberkern *et al.*, 2015; Pickard *et al.*, 2015; Pickard *et al.*, 2018). Qualitative studies (Rand and Malley, 2014) and cross-country comparisons (van den Broek and Grundy, 2018) have also found positive effects of service receipt on carers' wellbeing. Very few studies on services and carers' outcomes have focused on young or young adult carers, nor have

studies looked at service receipt and impacts on education. One exception is a qualitative study by Dearden and Becker (2000) which found where families received good quality and reliable support and services this reduced young people's caring roles.

This paper therefore aims to explore the role of services provided to the person with care needs to support the young adult carer and prevent needs from developing in the first place, as set out in the Care Act and Children and Family Act. In doing so it seeks to help illuminate the extent to which the principles of this policy operate in practice for young adult carers, a question which has previously been investigated in relation to older carers (e.g. Lloyd *et al.*, 2019). Our paper focuses on young adult carers caring for disabled or older adults in England. In line with definitions used in practice, a young adult carer is a person aged 16 to 25-years old providing unpaid care. This age is of key importance in terms of employment, education and mental health (Kessler *et al.*, 2005; Eurofound, 2017). Our main research questions in this paper are to investigate the extent to which services are being received by the person cared for by a young person, and under what circumstances. Secondly, to explore quantitatively and qualitatively the relationship between receipt of services by the person with care needs and the effects of caring on young adult people's education, employment and health, areas in which young adult carers are known to experience considerable disadvantages as described above.

Methods and data

We used a mixed-methods approach: quantitative analysis of survey data and qualitative interviews with young people with caring responsibilities. A mixed-methods design enabled us to investigate patterns and associations as well as people's experiences, based on a critical realist ontological approach to answering the research questions (Bhaskar, 1989). Findings from each method contribute in different ways to a better overall picture. In addition, qualitative interviews enabled us to explore associations found in the survey data in further depth and detail.

In 2017, we collected primary data through a self-completed questionnaire and in 2018 carried out follow-on in-depth interviews with a sub-sample of survey respondents. Ethical approval for this study was obtained from the Social Care Research Ethics Committee (Reference: [anonymised]). Consent for the questionnaire was assumed from its voluntary self-completion. Consent for the interviews was discussed with participants and recorded verbally at the start of the interview. Participants were sent Information Sheets explaining the study, confidentiality, anonymisation of interview data, and the voluntary nature of participation in interviews.

Survey of young adult carers

Sample and data

Participants were recruited through young adult carer and other young people's services, groups and events; local authorities; schools, colleges and universities; and online communities for young people who provide care. The range of recruitment methods was intended to recruit a range of young adult carers, including people who may not identify as such. Our selection criteria for the survey was young people aged 16 to 25 living in England who provided care to an adult (aged 16 or older). We also aimed to be as inclusive as possible of young carers who are typically less well represented in national surveys, including those caring at higher intensities. The question used in the survey to identify those with caring responsibilities was 'Do you look after, or give any help or support to family members, friends, neighbours or others because of long-term physical or mental ill health/disability; problems with drugs or alcohol; problems related to old age? Do not count anything you do as part of your paid employment'. This was based on the questions on caring responsibilities in the 2011 Census (Office for National Statistics, 2011) and the Crime Survey for England and Wales (Office for National Statistics, 2016). Questionnaires were available online and as a paper version. Easy-read versions were available and translations in a number of languages also offered. In total, 188 young people aged 16 to 25 with caring responsibilities completed the survey.

Measures

Impact of caring on carers' employment, education and health

Impacts of caring comprised three derived variables based on questions about whether the young person's caring role affected their employment, education or health. Each question had a list of response options covering a range of possible effects, with an open-ended option for 'other'. We derived a binary variable for each domain whereby '0' represented no effect and '1' any effect. 'Not applicable' responses were not included in analyses. Because of the age of some of the respondents, this resulted in a lower sample size for the 'employment being affected by caring' variable. Questions on effects of caring responsibilities were based on validated questions from the 2009/10 Survey of Carers in Households (HSCIC, 2010); the Personal Social Services Survey of Adult Carers in England (NHS Digital, 2016a) and the Health Survey for England (NHS Digital, 2016b). Amendments to the survey were made after testing with young people who did not take part in the main study.

Care provision

Questions on care provision, hours and type of care were based on previously used and validated questions from numerous surveys, including the 2011 Census (Office for National Statistics, 2011) and the Health Survey for England (NHS Digital, 2016b). In our study, the two measures of unpaid care

provision were care hours and type of care provided. Care hours/type of care are measures of the level of unpaid care provided and have been used in similar research as an indicator of care need when direct information from the care-recipient was unavailable (e.g. Pickard *et al.*, 2018). More intensive care (hours and/or type) have been found to be significantly associated with poorer carer outcomes in previous research (e.g. King and Pickard, 2011; Authors, 2018). Our care hours variable was based on a question about hours of care provided in a 'typical' week with multiple categorical response options. We examined both the full five derived categories (less than ten, 10-19, 20-34, 35-49 and 50+) and a number of thresholds. The only statistically significant association was a threshold of ten or more hours a week. We therefore used a binary variable whereby '0' indicated less than ten hours care provision a week, and '1' indicated 10 or more hours a week. Type of care was categorised as (a) personal care provision and (b) emotional care provision. Personal care provision included helping with one or more of the following activities: getting the person in and out of bed; washing face and hands; having a bath or shower; dressing or undressing; using the toilet; eating, including cutting up food. Emotional care provision was based on a question that asked about keeping the person company or providing emotional support, motivation or supervision. In addition, because of the differential impact of mental health caring found in other research (Diminic *et al.*, 2018), a variable was derived to distinguish the care-recipient having a mental health condition ('1') compared to them not having a mental health condition ('0').

Receipt of social care services by the person with care needs

The variable for receipt of social care services by the person with care needs was based on responses to a question that asked the carer whether or not the following services were received: Home care worker/Personal Assistant/ paid carer; daycentre; lunch club; meals service; supported employment; community transport; social or key worker; mental health service; support with drug or alcohol problems; respite care; crisis or out-of-hours care; equipment or adaptations to the home; and free-text other option. Possible responses were yes or no to each service. Again, this question was based on validated questions asked in other surveys such as the Health Survey for England (NHS Digital, 2016b). We derived a binary variable whereby '0' was not receiving any services and '1' was receipt of any service. As well as whether services were received or not, the survey also looked at whether the carer perceived that the right amount of services were received or whether more were needed.

Covariates

Analysis controlled for factors known from previous research to be associated with the outcomes under study. These included care provision, carers' gender, age, mental health and being the sole carer (Aldridge, 2018; Diminic *et al.*, 2018; Pickard *et al.*, 2018). The variable used for carers' mental

health was based on the four-item version of the Patient Health Questionnaire (PHQ4 score). This ultra-brief measure of depression and anxiety has been found to be valid and reliable in the general population (Löwe *et al.*, 2010). The range of possible scores is 0-12 with higher scores indicating poorer mental health. Carers' mental health was not used as a covariate for the analysis of health outcomes. Carers' ethnicity was not significantly associated with the outcomes under study in this sample so was omitted.

Analysis

Firstly, descriptive statistics were used to report characteristics of the sample; receipt of services by the person with care need; and the care provision/care need factors associated with receipt of services. Chi-squared tests and tests of means were used to determine any group differences. We then used regression models to compare impacts of caring where the care-recipient received services compared to when they did not. As the outcome variables were binary, we used logistic regression multivariate models. Separate models were used for each outcome (employment, education and health). Models controlled for factors known from previous research to be associated with the outcomes under study as described above. The care provision covariate used varied by outcome, based on preliminary analysis to establish which care provision factor was significantly associated with outcome. Diagnostic tests for goodness-of-fit (Pearson test statistics) are reported for the logistic regression models. In this test, models that predict values not significantly different from observed values indicate good fit.

For all analyses, a significance level of 0.05 was used as the criterion to determine statistical significance and 0.10 to indicate marginal significance. We conducted the analyses using Stata 14.2 (StataCorp, 2015).

Interviews

Following analysis of results from the survey we wanted to explore the associations seen in more depth and explore possible explanations for those associations. We therefore carried out interviews four to twelve months after survey completion with a subset of young people who had completed our survey and who indicated they were willing to take part in further research. Within this population, sampling was purposive (Patton, 2014). We aimed to carry out interviews with carers from three subgroups represented in the survey: (i) formal social care services being received by the care-recipient but carer (respondent) perceives more services are needed; (ii) services being received, no more perceived as needed; and (iii) no services being received, more perceived as needed. In order to focus on higher-need carers we excluded carers where no services were being received, none were perceived as needed, and the young person was providing care for less than ten hours a week. We

aimed to recruit 16 survey respondents to take part in interviews. This number was chosen so that different survey subgroups could be represented, and a range of experiences explored. The resultant sample size was 14 participants.

Participants were given the option to take part either by phone or in person. All but one chose to be interviewed by phone, and we worked with participants to allow interviews to occur at a time and place where they could speak freely, rescheduling where necessary. The interviews were semi-structured, with a topic guide used to ensure all areas were covered. Topics were informed by findings from the survey analysis. The interviews explored in further depth participants' experiences of the care-recipient receiving or not receiving services; whether the carer perceived enough services were being received; and perceived relationship between receipt of services, non-receipt of services/not receiving enough services and the young person's employment, education and health. Interviews explored negative and positive effects of receipt or non-receipt of services and the possible reasons for this.

Qualitative analysis

Interviews were recorded and transcribed in full, with the permission of participants. Transcripts were read and coded by two researchers using a qualitative data software package (NVivo, 2015). Codes were gathered into themes, and themes were re-examined and recoded to reflect emerging interpretations of the data. Whilst the analysis began deductively, exploring the specific service-use/outcome relationships seen in the analysis of the survey data, themes also emerged inductively from the data. As themes emerged, transcripts were re-examined for evidence related to the theme, with efforts made to check for counter-examples and exceptions. The software allowed side-by-side review of the same codes from different participants and facilitated organisation and reorganisation of coding categories to represent eventual themes. In presenting the results below, we use pseudonyms and have further anonymised the results by removing potentially identifying information.

Results

The following section firstly describes the survey and interview samples and then presents quantitative and qualitative findings on service receipt by the person cared for by a young person, what care need factors were associated with receipt of services, and the relationship between receipt of services and the effects of caring on young people.

Sample characteristics and carers' outcomes

Table 1 shows the characteristics of the survey sample; impacts of caring; care provision and care need. The majority of the sample were female (72%) and the average age was 18.6. A third (36%) were the sole carer. Three-quarters provided care for ten or more hours a week, just over half provided personal care and three-quarters provided emotional care. Just over a half (57%) were caring for someone with a mental health condition. Mean age of commencing care provision was twelve years old and mean duration of caring was seven years. Two-thirds (69%) of young people reported that caring affected their employment; 75% that caring affected their education; and almost 90% that caring affected their health. All but one of the interviewees was female, and the average age was 19.9 years. Just over half were the sole carer. Thirteen were providing care for ten or more hours a week, thirteen were providing emotional care, and half were providing personal care.

<TABLE 1 ABOUT HERE>

Are services being received by the person with care needs and under what circumstances?

Table 2 reports findings from the survey on receipt or non-receipt of services by the person with care need; whether enough services were perceived to be received; and the care need and care provision factors associated with receipt of services. For 57% of carers the person they care for was receiving services. Providing more intensive care was associated with higher proportions of service receipt, although for personal care this was not significantly higher. For 43% of carers no services were being received by the person they care for. This was also the case for over a third (38%) of carers providing more than ten hours of care a week, a third (35%) of carers providing personal care, and over half (56%) of carers providing emotional care. Sixty percent of carers felt that more services were needed by the person they cared for. This was significantly higher for young people providing personal care compared to other types of care.

<TABLE 2 ABOUT HERE>

Relationship between receipt of services by person with care needs and impacts of caring on young adult carers' employment, education and health

Survey

Table 3 shows that, controlling for level of unpaid care provision, care-recipient having a mental health condition, and carer characteristics, young adult carers had five times as high odds of reporting that their employment was affected by providing care if the person they cared for was receiving services compared to if they were not receiving services (OR:5.89; 95% CI: 1.47, 23.6). Pearson

goodness-of-fit test showed that this model predicted values not significantly different from observed values, indicating good fit. There was no significant difference in the odds of education or health being affected by caring if services were received compared to if they were not.

<TABLE 3 ABOUT HERE>

Interviews

Findings from the survey suggest that, even controlling for the measures of care provision/care need available, receipt of services was not associated with less impact of care provision on young people's employment, education and health. Subsequent interviews explored the relationship between service receipt and impacts of caring in more depth, including possible explanations for the lack of association seen. Interviews found that there were two key themes related to service receipt for the person with care needs and effects of caring on carers. The first theme was replacement effects - i.e. the extent to which formal services 'replaced', removed, or reduced the need for the young person to provide care. The second theme was emotional effects (positive and negative).

In terms of replacement effects, interviews showed the ways in which services reduced impacts of care provision by replacing some of the care the young person was or would have been providing: *'It makes my life very much easier.....it means I don't have to stay at home sort of looking after people for long hours of the day or on weekends'* (Maanya).

This enabled young people with caring responsibilities to pursue activities such as paid employment: *'They've helped massively. If we didn't have the carers then I wouldn't be able to work'* (Ashley).

Or to have time for themselves:

'When they are here it's good for me because I know she's in good hands for at least, you know, a day. You know, she doesn't necessarily need me all day that day, so I could go out and do things that I want to do' (Hannah).

Services also helped the carer by reducing stress levels and anxiety about leaving the person with care needs. In addition, because caring takes place in a relationship, positive emotional effects experienced by the person having their care needs met were also experienced by carers: *'It makes me happy to see her happy'* (Lucy).

'She's a lot happier now [she is receiving the support needed] and she's not about to die all the time which is great and less stressful for me' (Maanya).

However, interviews showed that sufficiency of services - receiving enough or the right type – was key. Not having enough services appeared to impact on young adult carers' education and health in two main ways. Firstly, by not enough services being received to 'replace' unpaid care provision to an extent where it did not impact on the young person's education and/or health. In the quote below, Daphne's mother had mental ill health and physical disabilities and received three hours of formal care a week.

'But then that's not good enough with me being at college, I thought it's good getting her out but three hours is not good for my mum or for the person who's caring for her, they can't do much in that time.' (Daphne).

When asked how more services would have helped her personally, Daphne replied that, *'it takes a bit of the caring role and edge off you.'*

Not enough services could refer to type as well as, or instead of, amount of services. In the absence of the right type of services, young adult carers had to fill the gaps as the following quotes show:

'There's a lot of emotional caring with my mum...so it's just being there, making sure that if she wants to talk to me, I'll listen and if she's in the middle of a breakdown just try and bring her out of it..... If she's having a serious breakdown I might have to be on suicide watch. So, it might be that I don't get any sleep, or I get very little sleep because even if I'm not sat with her, I've still got to be alert just in case she gets up and tries to go in the kitchen or something' (Isabel).

In the situation below, services had been stopped because, the interviewee reported, of a lack of funding. As a result of services stopping, the young person was having to provide that support for her mother instead.

'So it means that my mum talks to me about a lot of stuff that she'd normally talk to a psychologist about – some of the time – or she'll just become really vacant and not talk to anyone. So it goes like from one extreme to the other.' (Jane)

Lack of services could also have negative effects on carers' mental health and wellbeing. Experiencing the person they cared for not having their needs met was stressful and upsetting for the carer, especially when they lived with the person they care for, as a majority of the young adult carers in our survey did. The following quote is one example:

'It's so stressful...just getting the help or the fact she's not getting the help she needs' (Cleo).

As can be seen in the quote below, an additional negative effect on the young person's mental health and wellbeing was anxiety about leaving the person with support needs without adequate, or any, support.

'My mum not having support, it made me constantly worry. Because even now, when she's – when I know she's bad, I'm like, am I going to come home to find my mum's in hospital or worse?' (Isabel).

In the following quote, which encapsulates the two main themes related to services of replacement effects and emotional effects, Daphne is thinking about what it would be like if her mother did receive more services.

'It would be amazing...it [would] mean I can go out with my friends and go to [the seaside] for the day because I know she'll be alright. It would be great, even with education as well, just giving me those extra few hours to revise, do my assignments...it would be very beneficial.'

Preventing future need, such as preventing a caring role having a negative impact on carers' lives, is a key part of current policy. It is also important because, as can be seen from Table 1, many young carers started providing care at a young age and therefore provided care during critical periods in their employment, education and mental health development. Preventing needs thus requires prompt and timely intervention. However, a recurrent theme from the interviews was delay in accessing and receiving services either in the first place and/or if services were stopped. Delay for services was experienced by many of the carers we interviewed. In relation to the two themes above, delays resulted in lack of replacement for care provided by young people and created stress.

Discussion

Receipt of services by the person with care needs

Our study showed that for 57% of carers, the person they care for was receiving services. Consistent with a general trend towards concentration of social care services among people with very high needs (Humphries *et al.*, 2016; House of Commons, 2018), a higher proportion of service receipt was seen among carers providing higher intensity care (hours and/or type). However, rather less encouraging is that, despite services being received, young people were still providing personal care, emotional care, and long hours of care. This may well be because not enough services were being received - 60% of carers in our survey felt this was the case and the interviews showed some of the ways in which there was a shortfall in needed services. For 43% of carers no services were being received by the person they care for and this was still the case for young people providing high hours of care, personal care and/or emotional care, suggesting that children and young people were filling the care gaps. Lack of formal services for these families and the subsequent reliance on children and young people has also been found in other research on young adult (Dearden and Becker, 2000) and young (Cheesbrough, 2017) carers. The combination of no support and insufficient or inadequate support seen in our study represents a large gap in service receipt. In Arksey's framework of rationed care, insufficient services

represents rationing by dilution - reducing the quantity and in many cases the quality of services provided (Arksey, 2002).

Receipt of services by person with care needs and impacts of caring on young people

Previous research found that receiving services was associated with better outcomes for the working age and older carers of those receiving the services, particularly with regards to their employment (Geyer and Korfhage, 2015; Haberkern *et al.*, 2015; Pickard *et al.*, 2015; Pickard *et al.*, 2018). Services have also been linked to better carer wellbeing (Rand and Malley, 2014; van den Broek and Grundy, 2018). Like these studies, we also found instances where provision of services supported carers', employment and mental health, and also their education. Services supported young adult carers in two main ways, and facets of these themes emerged throughout the interviews. Firstly by replacing (some of) the care young people provided - prevention or mitigation in Purcal's framework - leaving them time to pursue other activities. This replacement effect has been seen for other age carers (Pickard, 2011; Verbeek-Oudijk *et al.*, 2019) and is consistent with the Care Act framework. Secondly, as has also been seen in previous research (Pickard *et al.*, 2018), adequate services could have positive emotional effects, by seeing the person get their needs met and by relieving stress and anxiety. However, in contrast to previous studies, quantitative findings from our study showed that receipt of services by the person with care needs was associated with a higher likelihood of survey participants reporting that their employment was affected by caring and no difference in the likelihood that their education or health were affected by caring.

One reason for the disparity with previous research may be to do with the extent to which the right amount or type of services was being received. In our study, we saw insufficiency of service receipt in a number of ways. Firstly, more services were perceived to be needed by a large proportion of the study sample. Secondly, even when services were being received, the majority of young people were still providing levels and types of care that have been found in previous research (Pickard, 2008; National Union of Students, 2014; Sempik and Becker, 2014) to be associated with greater impacts on young people's employment, education and health. Thirdly, interviews showed in detail the ways in which services received were in many cases not received in the right amount and/or type to meet care needs and the ways this affected carers' lives. In a mirror of the ways services could positively affect young people, the ways in which not enough, or no, services negatively impacted on carers were insufficient replacement effects and/or negative emotional effects. Negative emotional effects included stress and anxiety. Absence of (adequate) replacement care, meant that many young carers took on these care tasks themselves impacting on various aspects of their lives. Thus in the absence of enough services, the prevention or mitigation role in Purcal's framework could not be enacted. Nor could the requirements of the 2014 Care Act. Our study highlights some of the tensions between an

increase in rights for carers at a time of shrinking resources. Other research has found that austerity and resultant funding constraints on local authorities have resulted in difficulties in implementing the provisions of the Care Act for older carers (Lloyd *et al.*, 2019). There may be additional reasons as to why families with young adult carers may not be getting the support they need. These include barriers to access, cost, preference, and concerns about involving social services (Dearden and Becker, 2000; Institute of Health Equity, 2018). Young adult carers' age may be an additional barrier to getting support.

Young adult carers' age, and lifestage, is the second possible reason for the divergence of our findings from previous research on services and carers' outcomes. Previous research focused on mid-life or older carers, who usually start caring in mid- or late-adulthood. In contrast, many of the young people in our survey had already been caring since a young age and during known critical periods for education, employment and mental health (Kessler *et al.*, 2005; Eurofound, 2017). Preventing needs from arising in the first place is a key part of current policy for young adult carers and is especially important because of the life stage they are at and the possibility of long-term consequences. However, in our study young people were still experiencing impacts on their employment, education and health suggesting prevention of these impacts had not occurred. Furthermore delays in accessing and receiving services seen in our study may mean that opportunities to intervene during critical periods pass and care-recipients' health and/or the caring situation may also deteriorate in the meantime. Delay also resulted in both lack of replacement care and creation of additional stress. Delays – another aspect of rationed care in Arksey's framework - may worsen during times when resources are limited and wait times long (Humphries *et al.*, 2016).

Strengths and limitations

Our survey collected cross-sectional data so we could explore potential associations between receipt of services and impacts of caring in the survey rather than explanations for those associations. However, the interviews did allow us to explore potential mechanisms of influence. In our study, we used information about care provision as a measure of care need also. Although used extensively in previous research (e.g. Pickard *et al.*, 2018), these measures may not have fully captured the extent or nature of care need and as such, this effect may not have been sufficiently controlled for.

Our sample is based on a self-selected group of participants and although we recruited through a wide range of methods and fora, this may affect the generalisability of the findings. The proportion of carers providing care for ten or more hours a week is much higher than, for example, in the 2011 Census, and whilst the Census prevalence is considered to be an underestimate (Vizard *et al.*, 2018), our study participants were nevertheless a group providing high-intensity care. As impacts of caring

are greater at higher hours and we aimed to be as inclusive of this group as possible, this is not necessarily a disadvantage for our study. There is a possibility that we have excluded from this study people who do not identify as 'carers'. However, the question we used to identify carers used phrases such as 'look after', or 'give any help or support to' rather than 'carer'. Furthermore this question included specific mention of helping or supporting someone with mental ill health or problems with drugs and alcohol as this has been found to identify a more representative range of young carers (Cheesbrough *et al.*, 2017; Vizard *et al.*, 2018). Additionally, in some cases support workers helped young people who had difficulties doing so complete the questionnaire, which also helped widen the range of young people participating, including those typically under-represented in national surveys.

This range of participants and experiences is a strength of our research. Another strength is the mixed-methods design, allowing us to explore in depth some of the patterns we observed. This enabled our study to contribute to an understanding of whether and how social care services for disabled, long-term ill or older people can also support the needs of the person that provides unpaid care for them. This 'dual perspective', and for younger carers, 'whole family approach' is an important part of social care policy and practice in England, and to varying extent to long-term care policy and practice worldwide. In particular, we are able to contribute to an understanding of receipt of social care services by people providing care during young adulthood and the role of such services in supporting them and preventing needs from developing in the first place, key provisions of current social care policy in England. This is an area where little research has been carried out, especially since the Care Act, which has also been a period of particularly deep cuts to social care budgets and ongoing fiscal austerity more generally.

Implications for policy and practice

Our study showed how in some cases social care services helped young people providing unpaid care by alleviating stress and reducing their caring responsibilities. Without these services it is likely that care provision by the young people would have been higher and more impactful. Young people reported the positive effect services could and did have on their ability to participate in employment and education and on their mental health, under certain circumstances, as Dearden and Becker also observed (Dearden and Becker, 2000). However, in our study, the amount of services received was often not enough to adequately alleviate caring responsibilities. The 2014 Care Act brought in legislation that extended young and young adult carers' rights to an assessment of their needs and for support to meet those needs. However, its enactment coincided with cuts to local authority budgets, which have hampered the ability of local authorities to implement many of those new rights (Carers Trust, 2016; Lloyd *et al.*, 2019). In this environment, many young adult carers appeared to still be carrying out high levels of care and experiencing impacts on many areas of their lives. This needs

addressing. The particular circumstances of young adult carers may exacerbate this situation. The timing of their care provision means that in the absence of early intervention, there may be a need in young adulthood for coordinated support beyond the social care system as well as within it (Aldridge, 2018). In situations where there is reduced provision of formal care services, the limited financial and other resources available to many young carers and their families may limit their access to alternatives such as self-funded or other informal support, the latter reflected in the proportion in our study who are sole carers. As well as the funding and eligibility context, understanding the other reasons why young people and their families are not receiving the services they need may also help with access and uptake.

References

- ADASS (2015), *The Care Act and Whole-Family Approaches*, London: ADASS.
- Aldridge, J. (2018), 'Where are we now? Twenty-five years of research, policy and practice on young carers', *Critical Social Policy*, 38: 1, 155-165.
- Arksey, H. (2002), 'Rationed Care: Assessing the Support Needs of Informal Carers in English Social Services Authorities', *Journal of Social Policy*, 31(1), 81-101.
doi:10.1017/S0047279402006529
- Becker, F. and Becker, S. (2008), *Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24*, London: The Princess Royal Trust for Carers.
- Bhaskar, R. A. (1989). *Reclaiming Reality: A Critical Introduction to Contemporary Philosophy*. London: Verso.
- Burchardt, T., Jones, E. and Obolenskaya, P. (2018), 'Formal and Informal Long-Term Care in the Community: Interlocking or Incoherent Systems?', *Journal of Social Policy*, 47: 3, 479-503.
- Care Act (2014), London: The Stationery Office (TSO).
- Carers Trust (2016), *Care Act for Carers: One year on*, London: Carers Trust.
- Children and Families Act (2014), London: The Stationery Office.
- Cheesbrough, S., Harding, C., Webster, H., Taylor, L., Aldridge, J. (2017). *The lives of young carers in England Omnibus Survey Report*, London: Department for Education.
- Colombo, F., Llena-Nozal, A., Mercier, J. and Tjadens, F. (2011), *Help Wanted? Providing and Paying for Long-Term Care*, Geneva: OECD Publishing.
- Commission for Rural Communities (2013), *Being a young carer in rural England*, London: Commission for Rural Communities.
- Dearden, C.N. and Becker, S. (2000), *Growing Up Caring: Vulnerability and Transition to Adulthood: Young Carers' experiences*: Youth Work Press.
- DHSC (2018), *Carers Action Plan 2018-2020 - Supporting carers today*, London: Department of Health and Social Care.
- Diminic S, Hielscher E, Harris MG, et al. (2018), A profile of Australian mental health carers, their caring role and service needs: results from the 2012 Survey of Disability, Ageing and Carers. *Epidemiology and Psychiatric Sciences*. doi: 10.1017/S2045796018000446.
- Eurofound (2017), *Long-term unemployed youth: Characteristics and policy responses*, Luxembourg: Publications Office of the European Union.
- Geyer, J. and Korfhage, T. (2015), 'Long-term Care Insurance and Carers' Labor Supply – A Structural Model', *Health Economics*, 24: 9, 1178-1191.
- Haberkern, K., Schmid, T., and Szydlik, M. (2015), 'Gender differences in intergenerational care in European welfare states', *Ageing and Society*, 35(2), pp.298–320.
- House of Commons (2018), *Health and Social Care Committee and Housing, Communities and Local Government Committee: Oral evidence: Long term funding of adult social care*, London: House of Commons
- HSCIC (2010), *Survey of Carers in Households 2009/10*, Leeds: HSCIC.
- Humphries, R., Thorlby, R., Holder, H., Hall, P. and Charles, A. (2016), *Social care for older people: Home truths*, London: Kings Fund.
- Institute of Health Equity (2018), *Reducing health inequalities through new models of care: a resource for vanguards*, London: UCL Institute of Health Equity.
- Keith, L. and Morris, J. (1995) 'Easy targets: a disability rights perspective on the "children as carers" debate', *Critical Social Policy*, 44/45: 36-57.
- Kessler, R.C., Berglund, P., Demler, O., Jin, R., Merikangas, K.R. and Walters, E.E. (2005), 'Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication', *Archives of General Psychiatry*, 62: 6, 593-602.
- King, D. and Pickard, L. (2013), 'When is a carer's employment at risk? Longitudinal analysis of unpaid care and employment in midlife in England', *Health and Social Care in the Community*, 21: 3, 303-314.
- Lloyd, L., Jessiman, T., Cameron, A., Smith, R. and Bezzina, A. (2019), *Support for older carers of older people: the impact of the 2014 Care Act*, London: NIHR SSCR.

- Löwe, B., Wahl, I., Rose, M., Spitzer, C., Glaesmer, H., Wingenfeld, K., Schneider, A. and Brähler, E. (2010), 'A 4-item measure of depression and anxiety: Validation and standardization of the Patient Health Questionnaire-4 (PHQ-4) in the general population', *Journal of Affective Disorders*, 122: 1, 86-95.
- National Union of Students (2014), *Learning with care: Experiences of student carers in the UK*, London: NUS.
- NHS Digital (2016a), *Personal Social Services Survey of Adult Carers in England*, Leeds: NHS Digital
- NHS Digital (2016b), *Health Survey for England*, Leeds: NHS Digital
- Office for National Statistics (2011), *2011 Census*, London: Office for National Statistics.
- Office for National Statistics (2016), *Crime Survey for England and Wales*, London: Office for National Statistics
- Olsen, R. (2000), 'Families under the microscope: parallels between the young carers debate of the 1990s and the transformation of childhood in the late nineteenth century', *Children & Society*, 14, 384-394.
- Pickard, L. (2008), 'Numbers of disabled adults who receive care from children and young people in England'. Report for Department of Health'. *PSSRU Discussion Paper*, London: PSSRU, LSE.
- Pickard, L., King, D., Brimblecombe, N. and Knapp, M. (2015), 'The Effectiveness of Paid Services in Supporting Unpaid Carers' Employment in England', *Journal of Social Policy*, 44: 3, 567-590.
- Pickard, L., Brimblecombe, N., King, D. and Knapp, M. (2018), 'Replacement Care' for Working Carers? A Longitudinal Study in England, 2013–15', *Social Policy & Administration*, 52: 3, 690-709.
- Purcal, C., Hamilton, M., Thomson, C., and Cass, B. (2012). From Assistance to Prevention: Categorizing Young Carer Support Services in Australia, and International Implications. *Social Policy & Administration*, 46(7), 788–806. doi:10.1111/j.1467-9515.2011.00816.x
- Rand, S., and Malley, J. (2014). Carers' quality of life and experiences of adult social care support in England. *Health and Social Care in the Community*, 22, 375–385. <https://doi.org/10.1111/hsc.12089>
- Sempik, J. and Becker, S. Young Adult Carers at College and University, 2014, Carers Trust: London.
- StataCorp (2015), *Stata Statistical Software: Release 14*, TX: College Station.
- Twigg, J. (1992), 'Carers in the service system', in J. Twigg (ed.), *Carers: Research and Practice*, London: HMSO.
- Van den Broek, T. and Grundy, E. (2018). 'Does long-term care coverage shape the impact of informal care-giving on quality of life? A difference-in-difference approach', *Ageing and Society*, 1-18. doi:10.1017/S0144686X18001708
- Verbeek-Oudijk, D., Woittiez, I. and de Boer, A. (2019). 'The Effect of Public Home-Care Expenditure on Unpaid Caring: Differences between the over-50s in Work and Not in Work.' *International Journal of Care and Caring*, 3 (2): 203–24. doi.org/10.1332/239788219x15488381886353.
- Vizard, P., Obolenskaya, P., and Burchardt, T. (2019), 'Child Poverty Amongst Young Carers in the UK: Prevalence and Trends in the Wake of the Financial Crisis, Economic Downturn and Onset of Austerity', *Child Indicators Research*. doi.org/10.1007/s12187-018-9608-6
- Wayman, S., Raws, P. and Leadbitter, H. (2016), *'There's nobody is there – no one who can actually help?'*, London: The Children's Society.
- World Health Organization (2015), *World Report on Ageing and Health*, Geneva: World Health Organization.