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# The lives of young carers in England omnibus survey report: Research report

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# The lives of young carers in England

**Omnibus survey report** 

Research report

January 2017

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With Professor Jo Aldridge - Young Carers Research Group - Loughborough University



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## **Executive Summary**

This research report presents findings of a survey of parents of young carers aged 5 to 17 and, where possible, young carers themselves aged 11 to 17. The survey was conducted across England by Kantar Public<sup>1</sup> between July 2015 and February 2016. A further week of fieldwork was conducted in June 2016. A 'comparison' survey of families not containing a young carer was conducted in February 2016.

The research forms part of a broader suite of research commissioned by the Department for Education that aims to serve as a baseline study of the lives of young carers in England and to help measure the effectiveness of legislative changes in improving the identification and support of young carers and their families. The research has been conducted in partnership with Professor Jo Aldridge at the Young Carers Research Group, Loughborough University.

#### Aims and objectives

The survey aimed to add to the evidence already gathered from an earlier qualitative study by quantitatively assessing:

- a) the nature of the care and support that young carers are providing;
- b) their perceived impact of their caring responsibilities on their own physical and mental health, education and development; and
- c) the types of support they are receiving, whether formal or informal.

The survey was conducted as a module on the Kantar TNS Face to Face Omnibus survey. This is a general survey which uses a quota sampling methodology to interview over 3,400 adults aged 16+ living in private households in England each week. However, without underlying probability based sampling we cannot calculate any margins of error around any estimate of the number of young carers and the socio-demographic characteristics of their families. This objective is instead being addressed by the introduction of a question on both the adult and young person's interview on the Crime Survey for England and Wales (CSEW) which uses a random probability sampling methodology.

In the feasibility study that preceded this survey, it was agreed that the working definition of a young carer for this research would be:

A child/young person under the age of 18 who provides care in, or outside of, the family home for someone who is physically or mentally ill, disabled or misusing drugs or alcohol.

<sup>&</sup>lt;sup>1</sup> Formerly known as TNS BMRB

The care provided by children may be long or short term and, when they (and their families) have unmet needs, caring may have an adverse impact on children's health, well-being and transitions into adulthood.

#### The survey approach

The survey questions [included in the face to face omnibus survey] were thoroughly tested for their clarity and we conducted cognitive interviews among young carer families to explore the interpretation of the questions among both adults and young people.

Given the very low incidence of young carers among the population, we had to ask the question identifying whether the household contained a young carer in over 79,629 households to find 420 which contained at least one young carer. This included children and young people caring for relatives or others outside the home as well as those caring within the household. For the 'comparison survey,' we ran part of the questionnaire with 304 parents of young people aged 5 to 17 or who were not young carers.

If the young carer was aged 11 to 17, and available for interview at the same time as their parent, we supplemented these results with a parallel interview with the young person both to triangulate their responses with those of their parents and to explore further their perception of their caring responsibilities. Some young carers aged 16 to 17 were additionally sampled as adults in the main Omnibus survey. In these cases, we conducted a 'young persons' interview but did not attempt to collect data from their parent as well. In total, we achieved 118 interviews among young carers. We applied the same criteria to interview young people in the comparison survey where possible and achieved 62 interviews.

#### The roles and responsibilities of young carers

#### Who they care for

The parents that we interviewed reported that most of the young carers aged 5 to 17 were caring for someone inside the home. Of these, over half (55%) were caring for their mother and one in four (25%) were caring for a sibling. The younger carers (aged 5 to 11) were more likely to be assisting with the care of a sibling whilst older carers (aged 16 or 17) were most likely to be caring for their mother. Although numbers were small, young people caring outside the home were most likely to be caring for a grandparent but also for parents or siblings who they did not live with.

#### Type of care provided

Nearly eight out of ten (78%) were reported by their parents to be undertaking practical tasks as part of their caring responsibilities, such as cooking, cleaning, doing paperwork or helping with household chores. As might be expected, caring responsibility increased

with age. Over one in four (26%) were providing nursing care and parents considered over half (57%) also provided emotional support. Those caring outside the home were less likely to be undertaking nursing care (11%) but were providing almost similar levels of practical (68%) and emotional support (64%).<sup>2</sup>

#### Time spent caring

Although the majority of parents of young carers (53%) reported that their child was providing up to an hour or so of care a day during the school or college week, around one in seven (14%) reported four or more hours caring each day rising to over one in four (26%) at the weekends.

#### Helping around the home

In both the young carer and 'comparison' surveys we asked both parents and young people about the type and amount of help that the young person gave around the home. Compared to young people the same age, young carers were reported by their parents to be undertaking more tasks, more often and taking greater levels of responsibility for running the household. For example, over half (52%) of 12 to 15 year-old carers had helped cook a meal in the last month either 'some of the time' or a 'lot' compared to 32% of their peers in the comparison survey, and nearly one in four (24%) had looked after siblings without an adult present compared to 15% in the comparison survey. Young carers were also often helping with physical tasks such as lifting or carrying heavy things<sup>3</sup>, including one in four (25%) of 5 to 11 year olds helping in this way regularly compared to 15% of the comparison group.

#### Support for young carers

Fewer than one in five (19%) parents of young carers helping within the household reported that their child had received an assessment of the child's needs by the local authority, falling to 13% among those caring outside the household. Nearly two thirds (64%) were receiving no support, whether formal or informal. Of those receiving help, the most common source was a young carers' project<sup>4</sup>, followed by their school or college.

<sup>&</sup>lt;sup>2</sup> The questionnaire is appended to this report showing the definition given to respondents of the different types of support.

<sup>&</sup>lt;sup>3</sup> The respondent was free to define 'heavy' for themselves.

<sup>&</sup>lt;sup>4</sup> Young carers' projects are typically groups run by charitable organisations offering support to both young carers and their families.

#### The impact of caring

Previous research has shown that young people often find caring very rewarding, bringing emotional and psychological benefits, but it can equally place a strain on young carers' educational participation and ability to concentrate due to tiredness.

Most parents across both the face to face and comparison surveys reported that their children were happy at school and considered they were attending well and performing better than average. However, parents of young carers were significantly more likely than those in the comparison survey to report that their child was being bullied. The greatest difference was among 16 to 17 year olds of whom over one in five parents (16%) considered their child was being bullied, compared to only 4% of parents of children the same age in the comparison survey.

In terms of attendance, just over half (55%) of parents of young carers reported their child had been absent from school at least a few times in the last year compared to around one third of parents in the comparison survey. Further, 12% of parents of 12 to 15-year-old carers were aware that their child had fallen asleep at school at least a few times in the last 12 months compared to only 3% of parents of children the same age in the comparison group.

Whilst nearly all parents reported that their child was in good health, parents of young carers were less likely to say their child was in 'very good' health than those in the comparison survey. The greatest difference was among parents of 5 to 11 year olds where only 49% of young carers were reported to be in 'very good' health compared to 66% of those in the comparison survey.

#### The perceptions of young carers

When asked directly about their caring responsibilities, young people aged 11 to 17 who took part in the survey generally reported similar or higher rates of undertaking caring tasks than parents who were interviewed<sup>5</sup>. Again, young carers were spending more time in the home providing help and taking on more responsibilities. For example, 11% of the carers were helping with financial matters such as paying bills, compared to 1% of 11 to 17 year olds in the comparison survey.

In terms of their experience of school or college, the reports of young carers followed similar patterns to their parents. Nearly one in five (19%) 11 to 17 year-old young carers reported having trouble making friends compared to 12% in the comparison survey and again were more likely to report being bullied (16% compared to 3%).

<sup>&</sup>lt;sup>5</sup> Note that if the respondent was aged 16 or 17 they did not necessarily have a 'matched' parent interview.

When asked about being late for school, absenteeism and falling asleep, young people in both surveys were more likely than the parents to report all of these occurrences but the differences were most marked in the frequency with which it occurred to the young carers. One in ten (10% of) young carers aged 11 to 17 reported being late for school or college more than once a week in the last 12 months compared to only 1% in the comparison survey and about 5% had been absent from school more than once a week compared to 1% in the comparison survey. Similarly, young carers were more likely to report that they had fallen asleep at school at least a few times in the last 12 months (31%) compared to those in the comparison survey (20%).

We also asked the young people in both surveys for their assessment of emotions they had felt in the last week as an indicator of well-being. Whilst there were no significant differences between the groups we found that young carers were slightly more likely to have felt happy 'a lot' (64% compared to 55% in the comparison survey) but less likely to have had fun 'a lot' (69% compared to 76%) and more likely to have experienced anger 'a lot' (14% compared to 8%).

In 63 households we were able to make direct comparisons between the responses of the parent and the young person who had both taken part in the survey. Whilst reports of the factual information about the type of caring and responsibilities were quite consistent across the parents and their children, young carers did report slightly higher levels of absenteeism and lateness for school than their parents. However, it should be noted that this pattern seemed to occur in the comparison survey as well as among young carers. The young carers were also significantly less likely than their parents to consider that they were in 'very good' health (35% compared to 48%).

In all, these comparative results between parents and children show the importance of collecting information from both the parent and young person to build a full picture of the caring responsibilities and impact. Whilst parents may provide an accurate report of the care that is going on in the home, the responses of the young carers showed a sizeable minority having difficulty combining their education with their caring responsibilities.

It is clear that young carers in this survey are taking on much higher levels of responsibility in the home than their peers who do not have to provide care. In some instances, the effects of caring on children's physical and mental health and well-being are considerable and, without formal identification, assessment and support - including early help prevention-based interventions - these could have profound long-term effects on children's lives.

#### 1. Introduction

Kantar Public, in partnership with Professor Jo Aldridge, Director of the Young Carers Research Group (YCRG) at Loughborough University, was commissioned by the Department for Education (DfE) to conduct a programme of research investigating the lives of young carers in England. The research was designed to help inform the implementation of the 2015 Care Act requiring local authorities to identify and assess the support needs of any young carer – no matter how much or what type of care they provide.

The programme involved multiple objective strands ranging from a robust estimate of the prevalence of young people with caring responsibilities through to developing an in-depth understanding of the lived experience of young carers.

#### **Qualitative study**

The report of the qualitative study has been published separately<sup>6</sup>. This research was designed to find out more about the characteristics of young carers and their families; the nature of the care they provided; the impacts of caring responsibilities and the needs of both young carers and their families; experiences of support; and responses to support propositions developed in consultation with key local and national stakeholders. The research began with ten in-depth telephone interviews with individuals representing local authorities and national and local support organisations across England between October and December 2014. We used information gathered from these interviews to inform the design of 22 extended home visits conducted between January and March 2015. Finally, the results were explored and tested in a workshop conducted with nine young people who attended young carers' support projects.

Consistent with previous research, the study highlighted the pride that many young carers took in their role, but also the constraint it put on time to take part in other activities, particularly in the holidays. The adverse effects included anxiety, stress, tiredness, a strain on family relationships, restrictions in social activities and relationships, and under-engagement in education. Although many parents were keen to reduce the demands on their child, there was confusion about whether their child had received a young carers' needs assessment. The research also explored the demand for practical, emotional or information based support to help support young carers in their role.

<sup>&</sup>lt;sup>6</sup> https://www.gov.uk/government/publications/the-lives-of-young-carers-in-england

#### **National Statistics Survey to estimate prevalence**

According to the 2011 Census, there are almost 166,000 young carers aged 5 to 17 in England, although estimates from other studies using different methodologies or question wording to identify carers are much higher.<sup>7</sup>

Following an extensive development and cognitive testing stage, that is detailed in the Appendices to this report, a new question to identify young carers was developed that builds on previous studies and aims to identify carers with responsibilities both within and outside of the home. Whilst it was used in this survey, the quota sampling methodology of an Omnibus survey means it is not appropriate for generating an accurate national level estimate of prevalence.

However, a new question to identify young carers has now been adopted on the Crime Survey for England and Wales (CSEW), commissioned by the Office for National Statistics (ONS). The CSEW is a random probability survey, which includes approximately 32,500 households per year in England with data collected in each household from one adult aged 16+ and one child aged 10-15 (if resident) with an overall response rate of about 75%. As well as providing a robust sample, the survey already contained a question about carer responsibilities in the 10-15 year-old interview. The new question was introduced on the young persons' survey in June 2015 and on the adult survey in April 2016. Data is released annually by ONS on a financial year basis.

The previous young person's question read:

Some people your age may have to look after other people. This could be a brother or sister, a relative or someone else who is disabled or sick. Is there anyone like this who lives here with you that you have to look after on a regular basis?

- 1. Yes in this household
- 2. No

This was replaced by the following with an adapted wording to ask parents regarding children in the household.

Office for National Statistics (2013) <a href="http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html">http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html</a>: Table 1
 BBC, 16<sup>th</sup> November 2010 Cameron warns on child carer cuts <a href="http://www.bbc.co.uk/news/education-11757907">http://www.bbc.co.uk/news/education-11757907</a>

Some people your age provide help or support to people who are physically or mentally ill, disabled or misusing drugs or alcohol. This could be a parent, brother, sister, another relative or someone else.

Is there anyone like this who you have to look after on an ongoing basis? This could include people who live with you and people who do not.

- 1. Yes someone I live with
- 2. Yes someone I do not live with
- 3. No

The question is asked of (1) parents of 5 to 17 year olds about their child(ren), (2) young people aged 16 or 17 sampled directly as adults to take part in the survey and (3) children taking part in the 10 to 15 year-old interview. We anticipate sufficient numbers of young persons' interviews will be achieved later in 2016 to produce a robust estimate which can later be compared against figures from parents when numbers allow.

#### Survey of the nature and impact of carer responsibilities of young people

This report presents the development and results of a young carer survey conducted on the Kantar TNS Omnibus survey between July 2015 and February 2016, which aimed to identify and interview parents of young carers and, if aged between 11 and 17, the young carer themselves.

This strand of the research aimed to add to the evidence already gathered from the earlier qualitative study by quantitatively assessing:

- a) The nature of the care and support that young carers are providing;
- b) their perceived impact of their caring responsibilities on their own physical and mental health, education and development; and
- c) the types of support they are receiving, whether formal or informal.

The findings are compared to a 'comparison survey' conducted in households where the young person did not have caring responsibilities, again interviewing the parent and, where possible, the young person aged 11 to 17. This provides us with a unique opportunity to consider the roles and responsibilities of young carers in the context of the experience of their wider peer group.

The survey methodology is presented in section 2.

#### Defining a young carer for this research

In the feasibility study, we reviewed legal, practitioner and selected research literature to reach an agreed definition for this study that:

A young carer is a child/young person under the age of 18 who provides care in, or outside of, the family home for someone who is physically or mentally ill, disabled or misusing drugs or alcohol. The care provided by children may be long or short term and, when they (and their families) have unmet needs, caring may have an adverse impact on children's health, well-being and transitions into adulthood.

The process by which we selected this definition is outlined in Appendix A. It was agreed that this definition is sufficiently concise for research purposes and recognised the following important dimensions of caring:

- Makes appropriate reference to the legal age of children (ie under the age of 18).
- Refers to the care of an identifiable relative, neighbour or friend.
- Includes care both within and outside the home.
- Is inclusive of the reasons that someone may need care: involving substance misuse as well as physical or mental illness or disability.
- Refers to the extent or duration of caring (which can be assessed through further screening/testing).
- Refers to the unmet needs of children and families, which, research tells us, is one of the main reasons why children take on care responsibilities in families and why children continue to provide care in the long term.
- Refers to the potential adverse impact of caring on children with respect to their health (which can be physical, mental or emotional health and can be established, through further screening/testing), well-being and transitions into adulthood (on the other hand, caring may also have positive consequences for some children, which can also be established through further screening/testing).

## 2. Survey Methodology

#### Selecting a mode of data collection

At the feasibility stage we evaluated the most appropriate mode of data collection in order to conduct:

- I. A survey of parents of young carers aged 5 to 17; and
- II. a 'comparison survey' of parents of all children aged 5 to 17.

When we considered how to ask about the caring responsibilities of young people, much of the difference in existing survey estimates stemmed from the method and instruments by which the data were collected. First, parents and children have different perspectives so it matters from whom the data are collected. Secondly, some instruments are effective at capturing temporary as well as ongoing caring or including a wider range of help provided.<sup>8</sup>

We began by reviewing the robustness of previous surveys of young carers against agreed criteria, whether in school or in home, face to face or self-completion. Further details of the findings are contained in Appendix C. We concluded that in home face to face data collection was the most appropriate method to ensure that the questions were clearly understood and asked in a consistent fashion of both parents and young people.

We then went on to test whether the questions were best asked directly face to face by the interviewer or via self-completion methods. We found a high level of engagement with the questions and little evidence of discomfort in discussing the subject with a researcher, although some did consider the 'impact' question to be quite negative and interviewers were briefed to anticipate the likely reaction to this question in the field.

Although ideal for estimating prevalence, it was not feasible to run the full survey of caring responsibilities on young people on an existing National Statistics random probability survey due to cost and pressure of content on existing surveys. A more cost effective solution was to separate the measurement of prevalence from this research about the nature and impact of caring, which could be conducted using a quota sampled face to face Omnibus survey. For this purpose, we used the Kantar TNS Face to Face Omnibus survey. This is an in home survey of towards 1,500 adults each wave, aged 16+ living in private households in England, with one or two waves being conducted each week. The survey used random location sampling which, although less precise than a random probability survey, used very tight comparisons on demographic quotas that

<sup>&</sup>lt;sup>8</sup> Becker S (2007) Global Perspectives on Children's Unpaid Caregiving in the Family. Research and Policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa in Global Social Policy, Vol 7(1), 23-50

must be achieved within small sampled areas to achieve a more representative sample than can occur on many quota surveys. Further details about the survey and its sampling methodology are also given in Appendix D.

#### Selecting who to interview

The research design aimed to collect information about the nature and impact of caring responsibilities from parents of 5 to 17 year-old carers and, if available for interview at the same time, the young carer themselves. At the feasibility stage, we investigated the minimum age at which a young person should be invited to take part in the survey directly. Consideration was given to the ethical issues of informed consent and impact of interviewing young carers as a group with multiple vulnerabilities<sup>9</sup>, alongside their ability to comprehend the questions as intended by the research. On the basis of both desk review and cognitive testing of the survey among young carers, it was agreed that young carers aged 11 to 17 years old would be selected. This is, in fact, slightly higher than the minimum age of ten for inclusion in the young person's interview on the Crime Survey for England and Wales. For young carers below age 11, the parent interview would be conducted without triangulation against any child survey.

To place the results in context and compare the responsibilities of young carers to young people more widely, we also designed a small national survey of parents and children aged 11 to 17 in households that did not contain a carer. Using the Kantar TNS Face to Face Omnibus survey again, all parents of 5 to 17 year olds were interviewed, plus an interview with the young person themselves if they were at least age 11 and available for interview at the same time.

Further details of the consideration given to the age at which to interview young people are given in Appendix B.

#### Eligible sample assumptions

Using the range of estimates of prevalence given in previous research we anticipated identifying a young carer in at least 2% of interviews that we conducted with parents of 5 to 17 year olds. We also planned to supplement this with screening questions asked of 16 or 17 year olds who had been sampled directly to take part in the adult survey. In total, we estimated that within each wave of the survey we would interview at least 350 adults who were eligible for the screening question either as a parent or a 16 or 17 year-old respondent to the main survey. This was estimated to yield a minimum of seven interviews per wave within a 'young carer household'.

<sup>&</sup>lt;sup>9</sup> Aldridge, J. (2015) *Participatory Research: Working with Vulnerable Groups in Research and Practice*. The Policy Press: Bristol

If the Omnibus interview was a 'parent interview' we then attempted to interview the young carer if they were aged 11 to 17 and available at the same time. If there was more than one young carer in the household (which occurred in about 20% of households) priority was given to selecting an 11 to 17 year-old so they could be interviewed as well as the parent. If there was more than one young carer aged 11 or older available, a random allocation system was used to select who would be sampled.

#### **Questionnaire development**

The survey questionnaire (Appendix G) was subject to a thorough development stage given the many challenges to identifying and researching the caring responsibilities of young people in a national survey. Many families do not identify with the term 'young carer' and may also be reluctant to disclose the nature and extent of children's caring responsibilities whether to a researcher, the school or local authority. <sup>10</sup> Fears range from bullying and stigmatisation of the young person, because of the conditions of the parent(s)<sup>11</sup> they are caring for, through to the risk of intervention by social services or even of the young person being taken into care. <sup>12</sup>

The starting point for the questionnaire development was to collate and review existing questionnaires and research tools, which attempt to identify young carers and collect information about the nature and impact of the caring they undertake. Such questionnaires were identified through direct knowledge of the research team and DfE, and through the review of literature in the methodological review. Questions were reviewed under three broad categories:

- 1. Questions which identified young carers.
- 2. Questions which collected characteristics of the young carers' circumstances with respect to the people for whom they care and the nature and extent of the care they provide.

<sup>&</sup>lt;sup>10</sup> Smyth C et al (2011) 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers in Journal of Youth Studies, Vol 14, Issue 2 p145-160

<sup>&</sup>lt;sup>11</sup> The Princess Royal Trust found 68% of young carers had been bullied at school. The Princess Royal Trust for Carers (2010), 'Supporting Young Carers - A Schools Resource Survey' http://static.carers.org/files/final-survey-results-2010-5078.pdf

<sup>&</sup>lt;sup>12</sup> Aldridge, J. and Becker, S. (1993) Children who care. Inside the world of young carers. Leicestershire: Department of Social Sciences, Loughborough University; Moore T and McArthur M (2007) We're all in it together: supporting young carers and their families in Australia. Health and social care in the community, 15 (6), 561-568; Department of Health (2010) *Recognised, valued and supported: Next steps for the Carers Strategy* 

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/213804/dh\_122393.pdf Para 1.3

3. Questions which collected information which may be used to evaluate the potential impacts of caring responsibilities on young carers.

We carried out the greatest scrutiny on questions used to identify young carers given its importance for both this study and for measuring prevalence on the Crime Survey for England and Wales. For each question found in the methodological review, Kantar Public applied a bespoke framework based upon the Questionnaire Appraisal System (QAS-99)<sup>13</sup>, which is a systematic approach to reviewing survey questions to examine issues such as whether the question can be read out easily, is clear, has adequate response categories, poses recall risks, or is biased in its wording. There are eight categories against which questions are appraised:

- a) Reading/instructions
- b) Clarity
- c) Assumptions/knowledge/memory/task difficulty
- d) Sensitivity/bias
- e) Response categories
- f) Order/Context
- g) Mode effects (if mixed mode)
- h) Other

Full details of the results of the review are contained in Appendix E.

Further, we considered other questions that had previously been used on surveys of caring responsibilities on young people in order to propose a short survey lasting approximately 10 minutes. As for all key stages on this project, the proposals were reviewed by a Project Steering Group comprising Departmental officials, research experts and representatives of young carer groups before embarking on cognitively testing a pilot questionnaire among 15 young carers and seven parents of young carers in January 2015. Some families were selected via a young carer support group that worked with families around the country, whilst we found others through online survey screening. Further details of the questions tested and their effectiveness is provided in Appendix F. The final survey that was agreed with the Department and Project Steering group is provided in Appendix G. The comparison survey did not require separate testing as it was a shorter version of the young carers' questionnaire.

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<sup>&</sup>lt;sup>13</sup> See http://appliedresearch.cancer.gov/areas/cognitive/gas99.pdf

#### **Achieved interviews**

Fieldwork was conducted in England over 45 waves of the Omnibus survey between July 2015 and February 2016 with a further two waves conducted in June 2016. The 'comparison survey' was conducted on a single wave of the Omnibus in February 2016.

Table 1 shows the steps by which we identified and achieved interviews with parents and young people.

Table 1 Achieved interviews on the Young Carer and Comparison Survey

	Young carer survey	Comparison survey
Total number of Omnibus waves survey conducted on	45	1
Total number of adults age 16+ interviewed	76,629	1774
Number of parents with children aged 5 to 17 in the same household	16,503	304
Number of parents identified as living with a young carer	420	n/a
Number of young people aged 11 to 17 interviewed after their parents	63	24
Total Number of 16 or 17 year olds interviewed directly without their parents	55	38

#### Weighting

Before analysis, the data was weighted for the following reasons:

- I. Given the quota sampling method, there was potential for the sample achieved to be less precisely representative of the population across all socio-demographic characteristics than if we had used a random probability method.
- II. In the parent interview, there was a lower probability of sampling a parent of a child aged 16 or 17 as those young adults have a chance of being the sampled adult for the survey themselves.
- III. In the young person interview, we screened all 16 and 17 year olds taking part in the Omnibus as well as parents of children aged 16 or 17.

For the survey of young carers we weighted the age distribution to reflect that reported from the 2011 Census question about caring responsibilities on young people<sup>14</sup>. This means that although we have not necessarily accepted the prevalence levels found in the 2011 Census, for the purpose of this analysis, we have accepted the relative proportions at each age. Two weights were generated: first for the distribution by age among 5 to 17 year-old carers to be used in the parent survey, and second for the distribution among 11 to 17 year olds to be used for the young persons' survey.

For the comparison survey, we first weighted the results to reflect the distribution by age in the general population for the same two groups using the Office for National Statistics 2015 mid-year estimates. We also adjusted for the fact that the wave of the Omnibus upon which the comparison survey was conducted contained a higher than expected proportion of respondents from Black and Minority Ethnic groups. The weight was derived from data from the Crime Survey for England and Wales for families with the same age children. The young carer survey was considered to be sufficiently representative not to require any further weighting.

Table 2 shows the distribution by age of the young carers for each of the surveys, before and after weighting, to match the distribution of their respective populations. As expected, the weighting adjusts for the under-representation of 16 and 17 year olds in the parent surveys and over-representation in the young person surveys.

Note also that the age distribution of the two surveys is very different. Not surprisingly, the young carers survey is skewed towards older teenagers who are more likely to take on responsibilities. This means that we should not make comparisons between all 5 to 17 year olds across the young carer and comparison survey as the average age of the young carer sample will be much higher than the comparison survey. We have, therefore, only compared the comparison survey results to the young carer survey within age bands of 5 to 11, 12 to 15 and 16 to 17 years old rather than as a whole group. We should also take into account that, within these age bands, the young carers are slightly skewed towards the older ages of each band rather than the more even distribution to be found in the general population.

Table 3 shows the ethnic background of the child in the two surveys and the results of reweighting the comparison survey to be more nationally representative.

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<sup>&</sup>lt;sup>14</sup> http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html

Table 2 Weighted distribution of age for young carer and comparison interviews

Age		Young ca	rer survey	,	Comparison survey			
	Parents		Young	carers	Parents Young people			people
le .	Weighting			Weighting				
	Before	After	Before	After	Before	After	Before	After
5	2%	1%			12%	8%		
6	3%	2%			12%	8%		
7	2%	2%			10%	8%		
8	4%	3%			8%	8%		
9	6%	4%			6%	8%		
10	7%	5%			6%	7%		
11	6%	6%	5%	8%	10%	7%	14%	14%
12	10%	8%	5%	10%	5%	7%	2% <sup>15</sup>	14%
13	11%	10%	11%	12%	8%	7%	5%	14%
14	13%	11%	9%	14%	5%	8%	3%	14%
15	13%	13%	9%	16%	9%	8%	7%	15%
16	12%	16%	29%	19%	4%	8%	29%	15%
17	11%	18%	31%	22%	5%	8%	40%	15%
Total*	420	420	118	118	304	304	62	62

<sup>\*</sup>Note that bases are unweighted throughout this report.

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<sup>&</sup>lt;sup>15</sup> In application, with only one respondent age 12, young people aged 11 or 12 were collapsed into one category for allocating a weight to avoid an excessively large weight being created.

Table 3 Child's ethnic group, parents' interview, young carers and comparison survey

Ethnic Group	Parents of young carers	Comparison survey parent	
	Weighted	Unweighted	Weighted
All white backgrounds	84%	70%	79%
All Asian backgrounds	7%	18%	11%
All black backgrounds	3%	6%	5%
Other (including mixed)	5%	5%	5%
Total responses	420	304	304

#### Note on statistical significance and tables

The Omnibus survey uses a quota sampling methodology rendering it technically inappropriate for calculating tests of statistical significance that are based on the assumptions of a random probability sampling methodology. However, as an indicative guide, we have referred to differences between the young carers and the comparison survey participants as 'significant' in the text when, had the sampling methodology been random probability, differences would have been statistically significant at the 95% confidence interval level after taking into account the design effects of the reweighting. Given sample sizes, many findings are not significant at this level but are discussed as of interest.

Where base sizes are smaller than 40 no tests of significance were carried out and percentages are bracketed [].

### 3. Parents' views of the lives of young carers

This section reports on what parents told us about the roles and responsibilities of the young carer in their household. Where appropriate, comparisons are made with the tasks undertaken and well-being of young people reported on in the comparison survey of parents.

The surveys consisted of 420 interviews with parents of carers aged 5 to 17 with comparisons. As described previously, if there was more than one young carer in the household (which occurred in about 20% of households), priority was given to selecting an 11 to 17 year-old so they could be interviewed as well as the parent. If there was more than one young carer aged 11 or older available, a random allocation system was used to select who would be sampled. Comparisons, where appropriate, were then made with the 304 comparison interviews conducted with parents of children aged five to 17. As the Omnibus survey on which this was conducted is a survey of individuals rather than households, we are limited in the amount of household and family composition information we hold beyond that of the young carer and the person they care for: a shortcoming that should be addressed in any future attempts to survey this group.

#### Who are young carers caring for?

375 young carers were caring within the home. Of these, over half (55%) of all young carers were looking after their mother and one in four (25%) were caring for a sibling. This is consistent with previous studies <sup>16</sup>. Fewer (19%) were caring for their father and a smaller group (5%) were caring for a grandparent or other relative <sup>17</sup>. Older children were more likely than other age groups to be taking care of their mother (58% of 16 to 17 year-old carers) whilst the youngest carers were relatively more likely to be helping to care for a sibling (37% of 5 to 11 year olds). (Figure 1; Table 4). In a small number of households (about 4%) the young person was caring for more than one person and three young carers were caring for someone within and outside the home.

<sup>17</sup> As a survey of individuals, the Omnibus survey does not collect family structure information. We know from previous research that lone parent families are over-represented among young carer households.

<sup>&</sup>lt;sup>16</sup> C Dearden and S Becker (2004) *Young carers in the UK, the 2004 report,* Carers UK and the Children's Society

Figure 1 Who young carers are providing care for in the household by age group

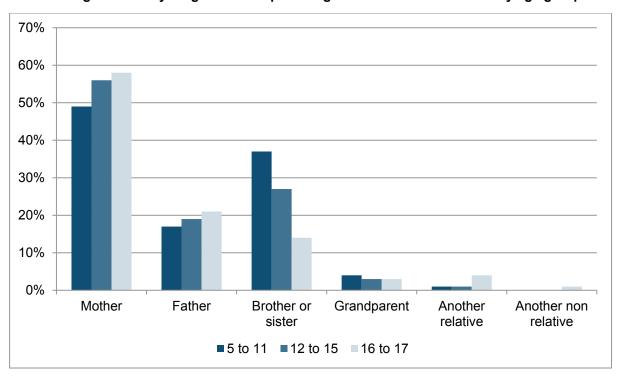


Table 4 Who young carers are providing care for in the household by age group

	5 to 11	12 to 15	16 to 17	Total
Mother	49%	56%	58%	55%
Father	17%	19%	21%	19%
Brother or sister	37%	27%	14%	25%
Grandparent	4%	3%	3%	3%
Another relative	1%	1%	4%	2%
Another non-relative	0%	0%	1%	*
Total	113	172	190	375

Percentages may add to more than 100 due to multiple responses

The numbers of children and young people caring outside the home (48) is too small to report by age group, but Table 5 shows that young people caring outside the household were often caring for a parent or sibling that they did not live with. About one in five (21%) were supporting someone who was not a relative.

Table 5 Who young carers are providing care for outside the household

	Total
Mother	16%
Father	5%
Brother or sister	10%
Grandparent	43%
Another relative	12%
Another non-relative	21%
Total	48

Percentages may add to more than 100 due to multiple responses

#### Type of care provided

Previous studies and the qualitative research that preceded this survey <sup>18</sup> have highlighted the wide range of caring roles and responsibilities that young carers undertake, from practical help around the home, to personal and nursing care, emotional support and household budgeting. Whilst this responsibility can have benefits, for example in terms of self-esteem, there is evidence that excessive, unsupported and long-term (more than two years) caring can have adverse effects on the young person's health, social activity, educational engagement and life chances. <sup>19</sup> This survey provided a unique opportunity, not only to study the care giving and responsibilities of young carers on a national scale, but also to consider how that differs from the norm among young people the same age.

http://www.ycrg.org.uk/youngCarersDownload/MCF Full Report 2.pdf

<sup>&</sup>lt;sup>18</sup> Department for Education (2016) The lives of young carers: qualitative study, Report by TNS BMRB <sup>19</sup> Aldridge, J. (2008) All Work and No Play? Understanding the Needs of Children with Caring Responsibilities. Children and Society, Vol 22, Issue 4, pp 253-264; Becker, S. (2007) Global perspectives on children's unpaid caregiving in the family: research and policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa. Global social policy, 7 (1), 23\_50.
Abraham, K. and Aldridge, J. 2010, Who Cares About Me? The Mental Well-Being of Young Carers in Manchester. Manchester Carers Forum; CAMHS and YCRG:

Of those children caring within the household, nearly eight out of ten (78%) were undertaking practical tasks defined in the survey as cooking, cleaning, shopping, doing paperwork or helping with household chores either 'some of the time' or 'a lot'. Over one in four (26%) were also providing nursing care for their sick or disabled relative, such as helping them to wash or to dress, give medication or helping them to move. Over half (57%) were reported to be providing emotional support, defined as sitting with them, trying to cheer them up, talking to them about their problems. Responsibilities for practical tasks tended to increase with age but involvement in nursing or emotional care was quite similar across the age groups ranging from 54% among 12 to 15 year olds to 60% among 16-17 year olds.

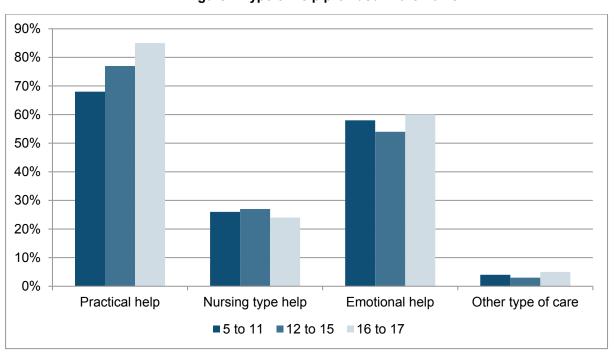


Figure 2 Type of help provided in the home

Table 6 Type of help provided in the home

	5 to 11	12 to 15	16 to 17	Total
Practical help	68%	77%	85%	78%
Nursing type help	26%	27%	24%	26%
Emotional help	58%	54%	60%	57%
Other type of care	4%	3%	5%	4%
Total	113	172	90	375

Percentages add to more than 100 due to multiple responses

Young people providing care outside the household were also very likely to be undertaking practical tasks (68%) or offering emotional support (64%) but less likely to be providing nursing care (11%).

Table 7 Type of help provided outside the household

	Total
Practical help	68%
Nursing type help	11%
Emotional help	64%
Other type of care	5%
Total	48

Percentages add to more than 100 due to multiple responses

#### Time spent caring

Most young carers spent more time caring at the weekends and during holidays than during the school or college week. But still, at least one in seven (14%) of all young carers were providing care for more than four hours a day on top of their studies (Table 8). At weekends and holidays, this rose to over one in four (26%). (Table 9).

Table 8 Hours spent caring on a school or college day

	5 to 11	12 to 15	16 to 17	All
0 to 1 hours	58%	53%	50%	53%
2 to 3 hours	22%	33%	38%	32%
4 or more hours	14%	14%	12%	14%
Total	124	196	100	420

Table 9 Hours spent caring at the weekend or in the holidays

	5 to 11	12 to 15	16 to 17	All
0 to 1 hours	42%	39%	36%	39%
2 to 3 hours	31%	37%	35%	35%
4 or more hours	27%	24%	29%	26%
Total	124	196	100	420

#### Helping around the home

We asked parents of young carers and the parents of young people without caring responsibilities about the jobs that children and young people undertook around the house. Here the greater amount of responsibility of the young carers compared to their counterparts in the comparison survey is clear.

On nearly all of the measures, young carers are providing substantially more help around the home than their peers in the comparison survey, particularly those aged under 12. These responsibilities tended to increase with age with 34% of 16 to 17 year-old carers looking after siblings without an adult present, and 17% dealing with financial matters. Young carers' ability to participate in activities outside the home was also limited by a high rate of staying in to keep a relative company (61% of all young carers).

Table 10 Parents' report of type of help given around the home in the last month, young carers and comparison survey

	Young Carers				Comparison survey			
	5 to 11	12 to 15	16 to 17	Total	5 to 11	12 to 15	16 to 17	
	Percentage reporting doing				'a lot' or 'some of the time'			
Cleaned bedroom	59%*	62%	71%	64%	41%	60%	[59%]	
Cleaned other rooms	38%*	47%	58%	48%	24%	36%	[35%]	
Washed up/loaded/unloaded dishwasher	39%*	57%	65%	55%	23%	55%	[67%]	
Gone to the shops to buy food	24%*	51%	59%	47%	13%	38%	[44%]	
Helped to prepare or cook a meal	29%*	52%*	60%	49%	18%	32%	[39%]	
Helped with decorating or DIY	11%	20%	26%	20%	15%	17%	[12%]	
Helped with lifting or carrying heavy things	25%*	60%*	63%	53%	15%	38%	[42%]	
Helped with financial matters (like dealing with bills)	2%	5%*	17%	8%	6%	0%	[0%]	
Worked part-time to help bring money in	1%	3%	17%	7%	5%	5%	[33%]	
Interpreted or signed for someone s/he lives with	4%	7%	10%	7%	5%	3%	[2%]	
Kept someone in the family company if they can't go out	50%*	61%*	68%	61%	20%	21%	[32%]	
Taken brothers/sisters to school	7%	9%	13%	10%	9%	7%	[3%]	
Looked after brothers/sisters with an adult nearby	37%*	33%	37%	35%	18%	21%	[14%]	
Looked after a brother or sister on his/her own	9%	24%	34%	24%	13%	15%	[16%]	
Provided nursing type care for someone s/he lives with	19%*	24%*	33%	26%	8%	0%	[14%]	
Total	124	196	100	420	199	79	26	

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results as responsibilities tend to increase with age.

#### Formal and informal support for young carers

Formal or informal support from others can help reduce the extent of young carer's responsibilities, although parents can be reluctant to disclose their condition and the support young carers are giving them to health and social care professionals, as well as schools.

With the implementation of the Care Act 2014 and the Children and Families Act 2014, local authorities now need to identify and assess the support needs of young carers, regardless of the type of support they provide<sup>20</sup>.

Our previous qualitative study found considerable confusion among both parents and their children as to whether they had received a young carer's needs assessment from their local authority. In the survey, we found just under one in five young carers (19%) providing care within the household had received a local authority assessment of their needs: consistent with previous research showing very low levels of identification and assessment of young carers.<sup>21</sup> Rates were much lower among those caring outside the home (13%).

Table 11 Whether the child has received an assessment by the local authority

	C	Caring out of the household 5-17			
	5-11	12-15	16 or 17	Total	Total
Had received an assessment	17%	21%	17%	19%	13%
Total	113	172	90	375	48

<sup>\*</sup>Note in three cases the young person was reported as caring both in and out of the household.

<sup>&</sup>lt;sup>20</sup> HM Government (2014) The care act 2014. London: Her Majesty's Stationery Office. Available online: HM Government: The care act 2014 HM Government (2014) Children and families act (96: young carers). London: Her Majesty's Stationery Office. Available online: HM Government: Children and families act <sup>21</sup> Barnardos. (2006) Hidden lives: Unidentified young carers in the UK. Available online: Barnardos Hidden Lives Young Carer Report; The Children's Society (2013). Hidden from View. The experiences of young carers in England.

We found nearly two thirds (64%) of all young carers in the survey were not receiving any support and, as found in previous research, they had particularly low levels of engagement with health and social services. <sup>22</sup>Younger carers (aged five to 11) were slightly more likely to be receiving support with one in four (25%) belonging to a young carer's project and one in ten (11%) were receiving support from their school or college.

Table 12 Whether young carer received support for themselves in their caring role

	5-11	12-15	16 or 17	Total
Social services	4%	4%	5%	4%
Health services	3%	2%	2%	2%
School/college	8%	15%	11%	12%
Young carers' project	23%	17%	10%	16%
A charity (other than a young carer's project)	3%	3%	2%	3%
Someone else	4%	6%	7%	6%
Don't know	5%	2%	2%	3%
None of these	57%	63%	70%	64%
Total	124	196	100	420

Percentages may add to more than 100 due to multiple responses

We asked whether the parent felt the support was meeting their child's needs, but in most cases, the numbers receiving support were too small to analyse further. However, for the two most common sources of support received, nearly two thirds of parents of young carers belonging to a young carers' project felt it was fully or partly meeting their needs, as did nearly all of parents of carers being supported by their school or college, although the numbers responding are too small to present by age group.

<sup>&</sup>lt;sup>22</sup> Dearden, C. and Becker, S. (2004) Young Carers and Education. Carers UK

As well as young carers, over half of the people they were caring for (55%) were not receiving support from either the local authority or charitable sector that might lead to the young carer being identified for support, although 12% were being supported by someone other than these organisations.

Table 13 Whether the person they care for received support

	Percentage receiving support
Social services	16%
Health services	22%
A charity	6%
Someone else	12%
Don't know	4%
None	55%
Total	420

Percentages add to more than 100 due to multiple responses

Among the most frequent providers of support, 90% of parents felt that social services were fully or partly meeting the cared-for person's needs, compared to 91% of those supported by health services and 96% of those being supported by someone else.

#### The impact of caring on young people

Previous research has shown that caring responsibilities can be very rewarding for children and young people - bringing emotional and psychological benefits, but they can equally place a strain on children's health, social activity, educational participation and employment opportunities. If caring is long term, unsupported and disproportionate to a child's age and level of maturity, it can have long-term impacts on that young person's transitions to adult and life chances.<sup>23</sup>

We asked parents to consider how their child, who was providing care, was progressing at school and in a number of other areas. To put these answers in context, we asked the same questions of parents in the comparison survey. We present these comparison survey results only within age group, as it is inappropriate to compare the entire group of 5 to 17 year olds, given very different age distribution of young carers compared to the general population. It is notable that across all age groups, parents of young carers were more likely to report that their child had difficulty making friends than those in the comparison survey (Table 14). Over one in four (26%) of parents of young carers aged 5 to 11 had this concern compared to only 7% of parents of the same age group in the comparisons survey.

Older teenagers in both surveys appeared to have similar difficulties concentrating in school, but there is a marked difference at younger ages, with 41% of parents of young carers aged 12 to 15 reporting difficulties compared to 16% of the non-carer parents of the same age group. Of concern also is the higher rate of experience of bullying reported by the parents of young carers. Nearly one in five (16%) parents of 16 to 17 year-old carers reported their child was being bullied, compared to only 4% among the same age group in the comparison survey. It is well established from other studies, including the qualitative research that forms part of this programme, that young carers are vulnerable to bullying from peers because they are perceived as different or their family, which may contain a sick or disabled adult, is not understood.<sup>24</sup>

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<sup>&</sup>lt;sup>23</sup> Abraham, K. and Aldridge, J. (2010), Who Cares About Me? The Mental Well-Being of Young Carers in Manchester. Manchester Carers Forum; CAMHS and YCRG: <a href="http://www.ycrg.org.uk/youngCarersDownload/MCF\_Full\_Report\_2.pdf">http://www.ycrg.org.uk/youngCarersDownload/MCF\_Full\_Report\_2.pdf</a>
Aldridge, J. (2008) All Work and No Play? Understanding the Needs of Children with Caring Responsibilities. Children and Society, Vol 22, Issue 4, pp 253-264.

<sup>&</sup>lt;sup>24</sup> The Princess Royal Trust found 68% of young carers had been bullied at school. The Princess Royal Trust for Carers (2010), 'Supporting Young Carers - A Schools Resource Survey' http://static.carers.org/files/final-survey-results-2010-5078.pdf

Otherwise, there are more similarities than differences between the young carers and their peers who are not providing care. Most parents reported that their child was happy at school, they were attending well and performing better than average. Differences in whether their child gets into trouble or hands in homework late are too small to be considered significant.

Table 14 Parents' rating of young carers' experience at school or college, young carers and comparison survey

	Young carers				Comparison survey			
	5 to 11	12 to 15	16 to 17	Total	5 to 11	12 to 15	16 to 17	
Percentage reporting 'strongly' or 'slightly' agree								
His/her grades are better than average	52%*	65%	63%	61%	68%	65%	[51%]	
His/her attendance is better than average	80%	81%	80%	81%	85%	90%	[85%]	
S/he enjoys going to school or college	87%	76%	85%	82%	86%	84%	[89%]	
I think s/he will leave school proud of his/her achievements	88%	86%	80%	84%	84%	87%	[91%]	
S/he gets into a lot of trouble	11%	12%*	5%	10%	9%	4%	[3%]	
S/he has trouble making friends	28%*	23%*	28%	26%	7%	9%	[5%]	
S/he gets involved in a lot of after-school activities	74%	57%	46%	57%	69%	62%	[41%]	
S/he often hands in homework late	15%	24%*	17%	19%	16%	12%	[15%]	
S/he finds it hard to concentrate in lessons	39%*	41%*	34%	38%	18%	16%	[35%]	
S/he is being bullied at school	18%*	20%*	16%	18%	7%	6%	[4%]	
Total	124	196	100	420	199	79	26	

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the experience is associated with increasing age.

We further explored a number of potential impacts of caring on young carers' attendance and concentration at school. In the qualitative study, many young carers demonstrated a strong commitment to doing well at school and had developed coping strategies, such as doing their homework at break times, so they had less to do at home. But for others balancing caring and school work was a significant challenge.

In terms of turning up for school on time, seven out of ten (70%) of the young carers had never been late for school in the last 12 months and there were no clear statistically significant differences from the comparison survey of young people in the same age groups.

Figure 3 Parents' report of whether the young carer had been late for school or college in the last 12 months

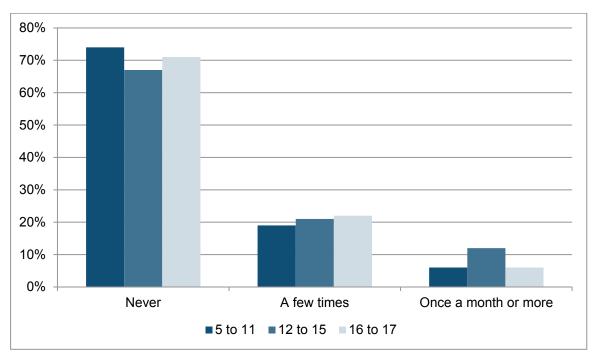


Table 15 Parents' report of whether the young carer had been late for school or college in the last 12 months and comparison survey parents' report of whether their child had been late for school or college in the last 12 months

	Young carers				Comparison survey		
	5 to 11	12 to 15	16 to 17	Total	5 to 11	12 to 15	16 to 17
Never	74%	67%	71%	70%	80%	70%	[57%]
A few times	19%	21%	22%	21%	17%	27%	[35%]
1 or 2 times a month	4%	5%	4%	4%	3%	1%	[5%]
1 or 2 times a fortnight	1%	3%	0%	2%	0%	1%	[0%]
More than once a	2%*	4%	2%	3%	0%	0%	[3%]
Total	124	196	100	420	199	79	26

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the response is associated with increasing age.

There were, however, indications that younger carers were more likely to have been absent from school or college in the last year. 57% of parents of 12 to 15 year-old carers reported that their child had been absent compared to 37% of parents of the same age group in the comparison survey, as did 54% of parents of carers aged 5 to 11 compared to 38% in the comparison group. Numbers of 16-17 year olds in the comparison survey were too small to make comparisons.

Figure 4 Parents' report of whether young carer had been absent from school or college in the last 12 months

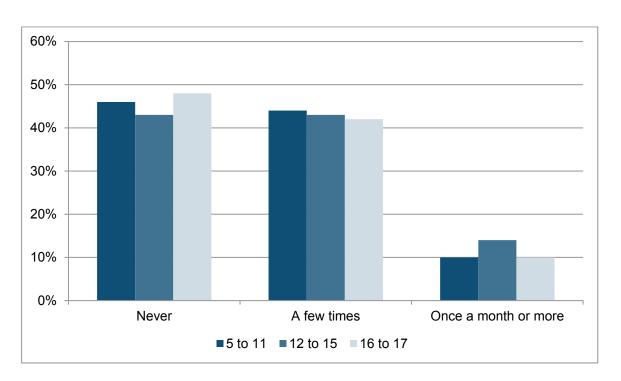


Table 16 Parents' report of whether young carer had been absent from school or college in the last 12 months and comparison survey parents' report of whether child had been absent from school or college in the last 12 months.

		Young carers				Comparison survey		
All children	5 to 11	12 to 15	16 to 17	Total	5 to 11	12 to 15	16 to 17	
Never	46%*	43%*	48%	45%	62%	63%	[36%]	
A few times	44%	43%	42%	43%	33%	36%	[58%]	
1 or 2 times a month	8%	9%*	5%	8%	3%	1%	[3%]	
1 or 2 times a fortnight	1%	3%	2%	2%	0%	0%	[0%]	
More than once a week	1%	2%	3%	2%	1%	0%	[3%]	
All young carers / comparison interviews	124	196	100	420	199	79	26	

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the response is associated with increasing age.

Finally, we asked if the child had fallen asleep at school or college in the last 12 months. Although older teenagers were quite similar, it is notable that 12% of parents of 12 to 15-year-old carers reported that their child had fallen asleep at least once compared to 2% of the same age group in the comparison survey.

Table 17 Parent report of whether the young carer had fallen asleep at school or college in the last 12 months and comparison survey parent report of whether their child had fallen asleep at school or college in the last 12 months

	Young carers			Comparison survey			
	5 to 11	12 to 15	16 to 17	Total	5 to 11	12 to 15	16 to 17
Never	90%*	88%*	86%	88%	96%	97%	[87%]
A few times	9%*	9%	11%	10%	3%	3%	[13%]
1 or 2 times a month	0%	2%	1%	1%	1%	0%	[0%]
1 or 2 times a fortnight	1%	1%	2%	1%	0%	0%	[0%]
More than once a week	0%	0%	1%	0%	1%	0%	[0%]
Total	124	196	100	420	199	79	26

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the experience is associated with increasing age.

Although nearly all parents of young carers reported their child's health to be 'good' or 'very good', it is notable that they were markedly less likely to consider their child to be in 'very good' health compared to parents in the comparison survey. The greatest difference was in their assessment of the youngest carers with 49% of parents of 5 to 11 year-old carers rating their child's health as 'very good' compared to 66% of comparison survey parents.

Table 18 Parents' rating of young carer's general health and comparison survey parents' rating of child's general health

		Young	carers	Com	parison su	rvey	
	5-11	12-15	16 or 17	Total	5-11	12-15	16 or 17
Very good	49%*	60%*	45%	52%	66%	75%	[66%]
Good	44%*	34%	46%	41%	28%	25%	[30%]
Bad	2%*	2%	8%	4%	0%	0%	[4%]
Very bad	1%	0%	0%	0%	4%	0%	[0%]
Don't know	2%	1%	0%	1%	2%	0%	[0%]
Prefer not to say	2%*	2%	1%	2%	0%	0%	[0%]
Total responses	124	196	100	420	199	79	26

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the experience is associated with increasing age.

# 4. The experiences and perceptions of young carers

We conducted a further set of interviews with 118 young carers aged 11 to 17 years old if they were either sampled as an adult themselves in the Omnibus survey, or were available to be interviewed immediately after their parent. If the young person was selected from the adult Omnibus survey, we did not conduct a parent interview. In this chapter, we look primarily at the reported household responsibilities and well-being of this group of young carers in comparison to 'comparison' interviews that were conducted with a further 62 young people.

## Help around the home

As with the parent survey, young carers reported much higher levels of helping around the home than those in the comparison survey on nearly every measure. Among statistically significant differences were the likelihood of cooking a meal at least some of the time (66% compared to 26%); staying in to keep someone company compared (69% compared to 35%) and helping with financial matters such as bills (11% compared to 1%). Not surprisingly, none of the young people in the comparison survey reported providing any nursing care compared to 33% of the young carers. (Table 19).

Table 19 Type of help given around the home by young people, comparing responses from the young carers and comparison surveys

	Young carers			Comparison survey
	11 to 15	16 to 17	All 11-17	All 11-17
	Percentage	e doing this	a lot or so	me of the time
Cleaned bedroom	57%	83%	67%*	47%
Cleaned other rooms	56%	75%	63%*	26%
Washed up/loaded/unloaded dishwasher	61%	83%	70%*	43%
Gone to the shops to buy food	56%	75%	63%	52%
Helped to prepare or cook a meal	58%	77%	66%*	26%
Helped with decorating or DIY	24%	44%	40%	28%
Helped with lifting or carrying heavy things	66%	78%	71%*	52%
Helped with financial matters (like dealing with bills)	7%	17%	11%*	1%
Worked part-time to help bring money in	2%	21%	10%	7%
Interpreted or signed for someone s/he lives with	9%	17%	12%	5%
Kept someone in the family company if they can't go out much	67%	70%	69%*	35%
Taken brothers or sisters to school	5%	11%	7%	10%
Looked after a brother or sister with an adult nearby	36%	41%	38%	27%
Looked after a brother or sister on his/her own	24%	41%	31%	23%
Provided nursing type care for someone s/he lives with	33%	33%	33%*	0%
Total	47	71	118	62

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the response is associated with increasing age.

## Experience at school or college

Again, there were many similarities between the young carers and young people in the comparison survey in terms of their enjoyment of school or college, reported attendance and involvement in activities. But consistent with the parents' survey, young carers were significantly more likely to report being bullied (16% compared to 3% in the comparison group) and, although not significant, somewhat more likely to report having difficulty making friends (19% compared to 12%).

Table 20 Young person's rating of their experience at school or college, comparing responses from the young carers and comparison surveys

		rs .	Comparison survey	
	11 to 15	16 to 17	All 11-17	All 11-17
		Percentage s	trongly or sli	ghtly agreeing
My grades are better than average	65%	61%	63%	71%
My attendance is better than average	66%	72%	68%	76%
I enjoy going to school or college	72%	76%	74%	80%
I think I will leave school proud of my achievements	85%	89%	86%	89%
I get into a lot of trouble	17%	10%	14%	8%
I have trouble making friends	21%	15%	19%	12%
I get involved in a lot of after-school activities	56%	38%	49%	51%
I often hand in homework late	28%	25%	27%	38%
I find it hard to concentrate in lessons	48%	41%	45%	44%
I am being bullied at school	21%	7%	16%*	3%
Total	47	71	118	62

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the experience is associated with increasing age.

Similar proportions of young carers aged 11 to 17 reported never being late for school or college (41%) as those in the comparison survey (49%), but there was a minority (10%) of carers who were late at least once a week, significantly different to only 1% of those in the comparison survey.

Figure 5 Whether been late for school or college, comparing responses from the young carers and comparison surveys

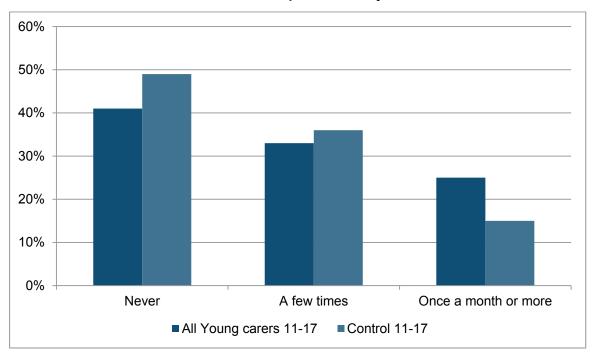


Table 21 Whether been late for school or college, comparing responses from the young carers and comparison surveys

		Comparison survey		
	11 to 15	16 to 17	All 11-17	All 11-17
Never	48%	31%	41%	49%
A few times	32%	34%	33%	36%
1 or 2 times a month	13%	11%	12%	10%
1 or 2 times a fortnight	0%	7%	3%	4%
More than once a week	6%	16%	10%*	1%
Prefer not to say	0%	1%	1%	0%
Total	47	71	118	62

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the response is associated with increasing age.

Young carers did have significantly higher levels of absenteeism from school than those in the comparison survey. Nearly three out of four (74%) had been absent at least a few times in the last year compared with around half (49%) of young people in the comparison group.

Figure 6 Whether been absent from school or college, comparing responses from the young carers and comparison surveys

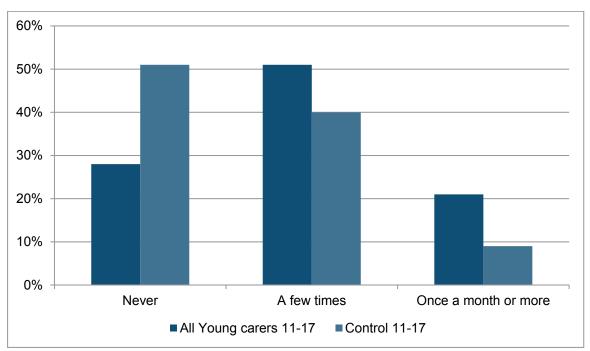


Table 22 Whether been absent from school or college, comparing responses from the young carers and comparison surveys

		Comparison survey		
	11 to 15	16 to 17	All 11-17	All 11-17
Never	26%	30%	28%*	51%
A few times	55%	43%	51%	40%
1 or 2 times a month	11%	13%	12%	7%
1 or 2 times a fortnight	2%	6%	4%	1%
More than once a week	4%	7%	5%	1%
Prefer not to say	0%	1%	1%	0%
Total	47	71	118	62

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the response is associated with increasing age.

Young people in both the young carer and comparison surveys were more likely than their parents to report that they had fallen asleep at school than their parents. However, both parents of young carers and the carers themselves were more likely to report falling asleep than in the comparison group. In total 31% of 11 to 17 year-old carers reported falling asleep at least a few times in the last year compared to 20% of those in the comparison survey.

Figure 7 Whether fallen asleep at school or college, comparing responses from the young carers and comparison surveys

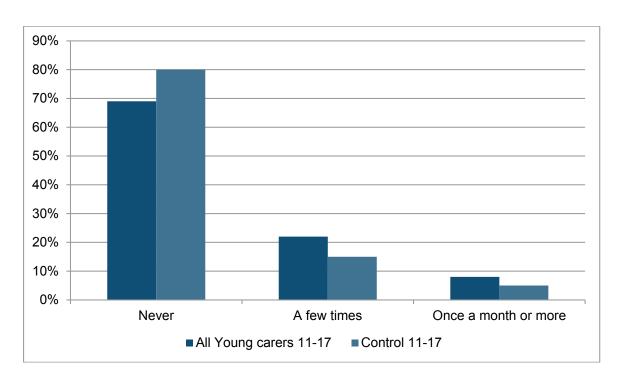


Table 23 Whether fallen asleep at school or college, comparing responses from the young carers and comparison surveys

		Comparison survey		
	11 to 15	16 to 17	All 11-17	All 11-17
Never	74%	62%	69%	80%
A few times	19%	28%	22%	15%
1 or 2 times a month	5%	3%	4%	0%
1 or 2 times a fortnight	0%	3%	1%	4%
More than once a week	3%	3%	3%	1%
Prefer not to say	0%	1%	1%	0%
Total	47	71	118	62

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the response is associated with increasing age.

## Health and well-being

In the related qualitative study, young carers did not consider their caring responsibilities to be impacting directly on their physical health but did perceive there to be impacts on their psychological health and well-being. In this survey, however, young carers were considerably less likely than those in the comparison group to report their health as 'very good' (37%) than those in the comparison survey (47%), and although numbers are small there was a greater proportion reporting 'bad' health (7%) than their peers who were not carers (1%).

Table 24 'How would you say your health is in general?' Comparing responses from the young carers and comparison survey

		Comparison survey		
	11 to 15	16 to 17	All 11-17	All 11-17
Very good	41%	32%	37%	47%
Good	54%	59%	56%	48%
Bad	5%	8%	7%	1%
Very bad	0%	0%	0%*	5%
Don't know	0%	0%	0%	0%
Prefer not to say	0%	0%	0%	0%
Total	47	71	118	62

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the response is associated with increasing age.

To assess mental health, we asked young people about different emotions that they might have experienced in the last week. We know that caring responsibilities can bring benefits to self-esteem and self-worth as the young people develop many life skills ahead of their peers. But caring can have a negative impact on the emotional well-being through tiredness, stress, depression and anxiety.<sup>25</sup> The picture from this survey is similarly mixed. Young carers were more likely to report having felt happy 'a lot' in the last week (64%) compared to the comparison survey (55%), but less likely to have had 'a lot' of fun (69% compared to 76%) or felt good about themselves a lot (45% compare to 56%). There is also some indication that they were more likely than their peers to have experienced anger a lot in the last week (14% compared to 8%). When we explored this in the qualitative study, young carers talked about experiencing anger and how they tried to manage these feelings by hiding them from their family.

Table 25 Emotions experienced in the last week, comparing responses from the young carers and comparison survey

	~	Young carers All 11 to 17		on survey 1 to 17
	A lot	Sometimes	A lot	Sometimes
Had fun	69%	26%	76%	22%
Felt sad	11%	29%	9%	20%
Felt lonely	7%	17%	4%	13%
Felt happy	64%	34%	55%	43%
Felt good about yourself	45%	46%	56%	43%
Felt angry	14%	46%	8%	49%
Total	118	118	62	62

<sup>\*</sup>Statistically significant from the comparison group of the same age at the p<=0.05 level.

Note that the responses to the young carers survey are slightly skewed towards the older ages within each band which will have a minor impact on results if the response is associated with increasing age.

Dearden, C. and Becker, S. (2004) Young Carers and Education. Carers UK; Frank, J. (1995) Couldn't Care More: A Study of Young Carers and Their Needs. London, The Children's Society.

<sup>&</sup>lt;sup>25</sup> Abraham, K. and Aldridge, J. (2010), Who Cares About Me? The Mental Well-Being of Young Carers in Manchester. Manchester Carers Forum; CAMHS and YCRG: http://www.ycrg.org.uk/youngCarersDownload/MCF Full Report 2.pdf

# 5. Comparing parent and child perceptions of caring responsibilities on young people

In 63 households, a young person was available to conduct the interview at the same time as the parent. Whilst the factual information given by parents and young people was broadly consistent, this gave us the opportunity to explore any discrepancies in perceptions between adults and young people about the impact of caring responsibilities. Results should, however, be treated with extreme caution and only taken as indicative given the small sample sizes. No reported differences were found to be statistically significant.

## Type of care provided

Reports of the type of care provided were generally consistent, although parents seemed slightly more likely to recognise the emotional help that the young carer gave.

Table 26 Type of care or help provided, comparing the responses of parents and young carers (caring in and out of the home)

	Parent	Young carer
Practical help	86%	87%
Nursing-type help	19%	29%
Emotional help	62%	58%
Other type of care	3%	3%
Total	63	63

## Help around the home

There was a reasonable degree of consistency between the parent and young carer reports of the type of help young carers provided around the home, although young people were slightly more likely to report that they cared for siblings (34% compared to 23%).

Table 27 Type of help provided around the home, comparing the responses of parents and young carers

	Parent	Young carer		
Percentage reporting doing a lot or some of the time				
Cleaned bedroom	69%	68%		
Cleaned other rooms	55%	64%		
Washed up/loaded/unloaded dishwasher	78%	72%		
Gone to the shops to buy food	61%	69%		
Helped to prepare or cook a meal	63%	58%		
Helped with decorating or DIY	26%	23%		
Helped with lifting or carrying heavy things	68%	69%		
Helped with financial matters (like dealing with bills)	10%	7%		
Worked part-time to help bring money in	11%	11%		
Interpreted or signed for someone s/he lives with	6%	7%		
Kept someone in the family company if they can't go out much	75%	72%		
Taken brothers or sisters to school	8%	5%		
Looked after a brother or sister with an adult nearby	32%	37%		
Looked after a brother or sister on his/her own	23%	34%		
Provided nursing type care for someone s/he lives with	28%	32%		
Total	63	63		

## **Time spent caring**

Reports of hours spent caring at the weekends or during holidays were broadly consistent across parents and their children. In the qualitative study that forms part of this research, children found it particularly difficult to recall exactly how much time they spent on caring tasks, and both adults and children found it difficult to assess what was 'typical' or 'average'. We would not, therefore, recommend drawing conclusions from any differences that we do observe.

Table 28 Hours spent caring on a typical school or college day, comparing the responses of parents and carers

	Parent	Young carer
0-1 hours	40%	45%
2-3 hours	49%	40%
4 or more hours	11%	15%
Total	63	63

Table 29 Hours spent caring on a weekend or school or college holiday, comparing the responses of parents and carers

	Parent	Young carer
0-1 hours	27%	22%
2-3 hours	40%	41%
4 or more hours	33%	37%
Total	63	63

## **Experience of school or college**

On most issues, parents and young carers shared similar opinions about young carers' experiences of school or college. On some measures, such as enjoying school or getting into trouble, attendance and handing in homework late the young carer's report was more negative than the parents, but this is consistent with indications from the comparison survey for this age group.

Table 30 Experience of school or college, comparing the responses of parents and young carers

	Parent	Young carer
My grades are better than average	60%	66%
My attendance is better than average	70%	61%
I enjoy going to school or college	87%	80%
I think I will leave school proud of my achievements	87%	89%
I get into a lot of trouble	12%	12%
I have trouble making friends	24%	28%
I get involved in a lot of after school activities	40%	41%
I often hand in homework late	24%	20%
I find it hard to concentrate in lessons	47%	46%
I am being bullied at school	25%	14%
Total	63	63

Although there were similar patterns in reporting of being late for school, being absent or having fallen asleep, parents reported a slightly more positive view than those of the young carers.

Table 31 Impact on school attendance and concentration, comparing the responses of parents and young carers

	Parents		Young carers			
	Been late for school / college	Been absent from school / college	Fallen asleep at school / college	Been late for school / college	Been absent from school / college	Fallen asleep at school / college
Never	58%	37%	77%	50%	30%	71%
A few times	29%	44%	21%	35%	52%	23%
1 or 2 times a month	7%	16%	0%	10%	9%	3%
1 or 2 times a fortnight	1%	0%	2%	0%	2%	2%
More than once a week	4%	3%	0%	5%	8%	2%
Total	63	63	63	63	63	63

### Health

In terms of health, the young carers were statistically significantly less likely than their parents to consider themselves to be in 'very' good health (35% compared to 48%), but very few reported poor health.

Table 32 General health, comparing the responses of parents and young carers

	Parents	Young carers
Very good	48%	35%
Good	43%	58%
Bad	10%	7%
Very bad	0%	0%
Don't know	0%	0%
Prefer not to say	0%	0%
Total	63	63

Whilst the sample for this part of the analysis was very restricted, the discrepancies between the parent and child's perspective about what is really going on at school underline the importance of bringing together evidence from both groups to build a picture of young carers' experiences.

## 6. Conclusions

This study has confirmed much previous research exploring the nature of young carer responsibilities and the impact this can have on their well-being, educational participation and social activity. By interviewing both parents and young people we have shown the importance of triangulating the evidence to first build a factual picture of the care that is being provided, perhaps relying more on the adult's recall, whilst exploring the perceived impact more closely with the young person. Young people were less likely than their parents, for example, to recognise their emotional caring role and tended to focus more on practical tasks that they undertook around the home. But parents were less aware, of the details of their child's participation and experience of school, and this was particularly the case among parents of older teenagers who were caring.

In terms of help around the home, young carers were consistently taking more responsibility than their peers both for their own day to day lives as well as undertaking chores, caring for siblings and helping with household finances in addition to looking after the person they cared for. While about half of the parents of young carers children were spending an hour or so of their day on a school or college day, a sizeable minority (14%) of parents reported their children were spending at least four hours a day with even more provided on the weekends.

Although the majority of children and young people were managing to combine their caring roles with their education, they were more at risk of being absent from school than their peers who did not provide care and to experience tiredness when in school. Differences were more pronounced among those in the early years of secondary education (aged 12 to 15) who were perhaps taking on more responsibilities around the home but less able to combine this with their studies than older carers.

There were also notable effects for some young carers in terms of physical and mental well-being. They were considerably less likely than their peers who did not provide care to report themselves in very good health, although few considered themselves to be in poor health. Similarly, although carers showed positive impacts of caring in terms of their happiness and self-esteem, for some there were feelings of anger on a more regular basis than their peers who were not carers.

As found in the qualitative research that preceded this survey, both parents and young carers consistently reported a higher likelihood of bullying and difficulties making friends among peers who might lack empathy towards or not understand their family situation. Where schools were providing support to the child, families found this to be very effective, but only about one in ten young carers were being helped in this way. Instead, nearly two thirds were not receiving any support, whether formal or informal and given less than half of the people they cared for were receiving support, they were unlikely to be identified via provision for the person with care needs.

Although the qualitative study highlighted fears that families have about disclosure — which is also well known from previous studies of young carers - and what this means in terms of intervention, this survey has highlighted the ongoing need for identification, recognition and assessment of young carers' needs. Early intervention can enable young carers to participate more fully in social and educational life and prevent long-term educational and health consequences for these young people.



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