



The  
Children's  
Society

# 'There's nobody is there – no one who can actually help?'

**The challenges of estimating the number of  
young carers and knowing how to meet their needs**

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By Sarah Wayman, Phil Raws and Helen Leadbitter

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We are hugely grateful to staff at young carers' services and other organisations who supported the study, for their help

in recruiting young people to the research, for completing the survey, for facilitating visits and research interviews and, in some instances, for being interviewed themselves.

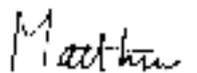
Thanks also to the expert stakeholders who were interviewed for the study, and to the external readers for their helpful input in finalising the report.

# Foreword

Young carers today face a greater set of challenges than ever before, yet too often they remain unrecognised and unassisted by the very systems and services that should be there to support them. This is exactly why efforts to research and understand the issues and social landscape that young carers and their families face are so very important. We need greater knowledge about the lives of young carers, so that we can be sure we are taking the most effective measures to improve them. Getting things right for young carers now is crucially important for their immediate development as young people and their longer term chances to thrive as an adult.

If we continue to move forward without a proper understanding of the myriad complex pressures that young carers face in their daily lives, too many of them will carry on falling through the gaps, facing unnecessary hardships and remaining hidden from the support services they desperately need.

It is therefore vital that services make a concerted effort to work together to both understand and assist young carers in their caregiving wherever possible, and I am immensely proud that once again The Children's Society is at the forefront on this issue, leading a call for change and advocating a better life for these exceptional young people with the best possible chances to flourish.

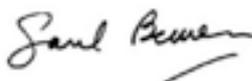


**Matthew Reed**, CEO  
The Children's Society

There is a quarter of a century of social research on young carers that provides the foundation for this important study. The report reviews the different methodologies and estimates of the number of young carers in the UK and highlights the on-going challenges in trying, first, to identify young carers from different circumstances (including those considered 'hard to reach'), and second, to meet the needs of young carers and their families.

The qualitative element of the study shows that caring has significant impacts on the lives, education, health and development of young people. What remains clear, despite decades of research, is that there is still a long way to go to ensure that most young carers have adequate and appropriate support that reduces their vulnerability, caring roles and promotes their health, wellbeing and full potential.

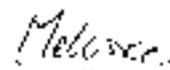
There are, however, some signs for optimism. New legislation relating to young carers, those they care for and the whole family, and reviewed here, has strengthened the rights of young carers today. Can our policy makers and service providers turn the hope offered by this legislation into positive outcomes for young carers and their families? The conclusions and ways forward offered in this report provide a framework for renewed action.



**Professor Saul Becker**,  
Pro-Vice-Chancellor and Head of  
the College of Social Sciences,  
University of Birmingham

When I read this research, I was given hope. Despite Government cuts and pressures on local services, there are those out there who want to help young carers, and that help that will make a significant impact in someone's life. As a champion, I've been able to meet a lot of other young carers and the issues like the ones discussed in this research are exactly what we talk about. They've done a good job at telling others what a young carer's life is like at a glance, and of explaining the issues that surround identification.

I've known people that have been caring for years without ever hearing the term 'young carer', but the findings in this research have the chance to improve the way young carers are both identified and supported by those around them – and give them a chance to have as much of a normal childhood as possible. Research about young carers is important, not just to the young people themselves, but to the people they're caring for. With more information comes more understanding and more help, and that's all young carers want really. Caring becomes a part of life, but if there's a way to make that even a fraction easier, then we'll take it.



**Melissa**,  
young carer

# 1. Introduction

Despite a body of research spanning nearly three decades, and the efforts of policymakers and practitioners to improve the situation, many thousands of children and young people across England have caring roles which they struggle to cope with and need support for.

Equally, there are many young people who are managing their caregiving responsibilities but who may benefit from the reassurance of greater understanding and acceptance by others of their role, and the option for some support when they need it.

In the 2001 Census, for the first time a question was asked to generate figures for the amount of 'unpaid care' in the UK. According to the 2011 Census there were 166,363 young carers (aged 5 to 17 years old) in England, an increase of almost 20% on the number identified in 2001. Whether this is a good estimate of the true scale of young people's caring responsibilities is open to question, but – if it is even broadly accurate – few of this large number of young carers are ever known to specialist support services. The reality is that most remain unidentified.

In 2014 a potential step-change in recognition and support for young carers arrived in the form of two pieces of new legislation: the Care Act, and the Children and Families Act. These gave local authorities greater legal responsibilities to ensure that young carers' needs are recognised and responded to, and could significantly improve the prospects for this group. But there is a long way to go to ensure this happens consistently for all.

This research looks at two key issues in relation to the caregiving responsibilities of children and young people. It asks whether, despite a series of research studies and two Censuses, we have an accurate picture of the scale of the phenomenon. And it assesses how the responsiveness of services to young people with significant caring roles – especially those who may not currently be accessing support – can be improved.

# Bina's story<sup>1</sup>



Bina says that she used to find her caregiving role stressful, particularly when she first took on the majority of responsibility for domestic tasks at home after her parents separated. At the time this was compounded by other things happening in her life - she struggled to get a place in a new school, she felt isolated and didn't have many friends she could talk to - and she became depressed. She started getting stress headaches and went to the doctor, who gave her a prescription for painkillers. After a while she overdosed on her medication.

As a result, Bina ended up in hospital and was referred to a crisis mental health team – a process which she found upsetting, and not particularly supportive. She can't recall anyone explaining the concept of 'young carers' to her, or suggesting that young people in her situation qualified for any kind of support. Eventually, though, she was referred to a young carers service locally, which she finds invaluable.

Now Bina's doing well, and she's got big plans. She's going to college and wants to apply for a scholarship to move overseas to study. But she's at a crossroads – her plans would mean leaving her father and her young brothers, and she doesn't think they would be able to cope without her.

Sabina, or Bina, is 17 years old. She lives with her father, whose vision is impaired and who is affected by depression. Bina helps to support him with a range of tasks. She helps with his paperwork and applications, as he struggles with reading and writing. She gets him to hospital appointments and supports him emotionally, as he can find it hard to remember things and often feels uncomfortable leaving the house. Bina also helps to look after her two younger brothers, getting them to school and supporting them in lots of ways when her father is ill. She cooks, cleans and shops to ensure that the household is running properly. And she worries about finances and feels sad that her brothers don't have a higher standard of living.

She says her caregiving role started when her parents' relationship broke down and she moved with her father and brothers to a new area (when she was about 13), but concedes that she's actually been helping to support various family members since she was a small child. However, as she explained when talking about the specialist project she attends, the concept of being a 'young carer' was alien to her:

'I didn't know what it was until I came to this service – you don't really think about it.'

So it's difficult for her to pinpoint exactly 'when' she became a 'carer'.

<sup>1</sup>This and all the other individual stories presented in the report have had details changed (including the name of the young person) in order to protect the identity of research participants who shared their experiences in confidence.

## 1.1 Research aims and methodology

The study was commissioned by the Big Lottery Fund. The research aims agreed at the outset with the Young Carers in Focus programme<sup>2</sup> were:

**1. To better understand why there has been an increase in the number of young carers identified (in the 2011 Census<sup>3</sup>).**

**2. To explore the needs of particular groups among young carers who may not currently be benefiting from accessible, inclusive services.**

Meeting the aims of the study required two separate projects, and further interpretation of the aims which had been specified in the original brief.

In relation to the first aim, on initial reading figures from the 2011 Census did indeed suggest that there had been an increase in the number of young carers in England compared to 2001. This could indicate that there were more children and young people caring for members of their family or others in their community than there had been 10 years earlier.<sup>4</sup> However, it could also be an outcome of a change in reporting behaviour by adults (who usually complete the Census forms), for example because they had

become more aware of, or better understood, the concept of 'young carers' in the intervening period or had become less inhibited about saying that this was a feature of their household. There could also be other less obvious reasons why the figure had changed.

In order to consider this, and to scrutinise more broadly what the figures and the change might mean, a review of research literature on young carers was undertaken to explore estimates of the incidence of young people's caregiving over time, and to look at how the role of 'young carer' had been understood and defined. This was complemented by a further review and analysis of the Census data and methodology (looking at how relevant questions had been asked and how data had been collected) to consider how well this linked to the definitions and methodologies employed by researchers, practitioners and policymakers in the field – and whether any of the attempts to estimate the prevalence of young people's caregiving were likely to have been successful in gauging the scale of the issue.

The second aim had been included in order to build on the

findings from the Census (with the assumption that the figures were a true indication of the scale and nature of young people's caregiving) – and additional research specifically around young carers (Hounsell, 2013), which had identified young carer groups that may be 'hidden'<sup>5</sup> from services. In particular, the following groups were said not to be present in young carer provision:<sup>6</sup>

- Children aged under 10 years old
- Black and minority ethnic (BME) children and young people
- Young adults aged 18 to 24.

The requirement to consider the needs of distinct (though potentially overlapping) groups presented a set of challenges for the second research project, especially given the resource and time constraints for the study.

This prompted a pragmatic decision to create a principally qualitative design, and to explore potential barriers to identification or support with a sample of young people already in contact with specialist services for young carers, who would be able to offer insights based on their experiences.<sup>7</sup>

<sup>2</sup> Young Carers in Focus is a Big Lottery-funded programme of activities to improve awareness and understanding of young carers, focused on empowering young people themselves to be involved. <http://www.youngcarer.com/resources/young-carers-focus-ycif>

<sup>3</sup> And other recent research, including 'Hidden from View' (Hounsell, 2013).

<sup>4</sup> n.b. The Census question did not restrict young caring to caring for family members – whereas other definitions have (see Chapter 3 below).

<sup>5</sup> In this context, 'hidden' means that young people with a caring role were not receiving support from specialist projects – though this could be for a variety of reasons (as discussed later in the report).

<sup>6</sup> See Hounsell, 2013.

<sup>7</sup> A more sophisticated design was proposed and partially implemented – though complications around compliance by the services taking part meant this had to be abandoned (see Appendix Two for more details on this, and for a discussion of some of the challenges around methodology which were encountered during field work for the study).

A sample of young carers was recruited through specialist 'young carer' services which offered a representation of young people from each of the three target groups.

Projects and services were approached in cities in four areas: the North West, West Midlands, South West and South East – regions that were highlighted in the 2011 Census data as having high proportions of young carers.

Practitioners from each young carers service were asked to complete a survey about who they worked with, what services they provided and how they delivered them. This was done partly to check the feasibility of selecting an appropriate sample, but also to help contextualise the young people's experiences.<sup>8</sup>

During this phase of making project contacts and negotiating access, published research literature relating to young people's caring (in particular to the excluded groups specified in the brief) was read and reviewed in preparation for the study and to inform the content of the qualitative interviews and focus groups.

To conduct the interviews a thematic guide was developed. The structure and wording for this was partly informed through consultation work with young carers at the 2014 Young Carers

Festival<sup>9</sup>, and a first version was piloted with a group of young carers in South East England who were not included in the final research sample.

Following some revisions to questions and to the format of the interview guide, a final version was drafted, but this was employed flexibly and each individual interview was governed by the need to follow a young person's story as it was shared. Consent was sought from parents, project staff and young people at each stage. In addition a range of techniques to engage with participants was used, including group discussions, portraits and drawing as appropriate. Interviews took place at young carer projects and in people's homes.

In total 45 young people took part in the interviews and, for a small subgroup within the sample (five young people), a more in-depth approach was taken. The young carer (and, on some occasions, siblings who were also carers) was interviewed on two occasions, with the second interview taking place around two months later. These interviews were conducted in the young person's home or in a nearby venue (eg a local cafe) to suit them. This was done to facilitate a more detailed examination of the family's circumstances and perspectives, and to look at whether there had

been any changes over time.<sup>10</sup> These interviews allowed for a greater rapport to be built with interviewees and offered additional insights into their lives.

For this group, if a young person was happy for an approach to be made (and subject to their informed consent) parents were also interviewed. Parents from all five families were interviewed, two in person and three via telephone. These multi-perspective case study interviews were helpful for understanding more about family dynamics within those families, and for discovering more about different views of family members on caring.

A number of professional stakeholders also participated in the study. Informal telephone interviews were carried out with 11 young carers service workers from across the country, to better understand the issues of service provision. In addition, three expert stakeholders (academics and strategic practitioners) were interviewed to explore their views on the challenges to identifying or supporting some groups of young carers.

More details on the methodology for the second project are given in Appendix Two.

All interviews were digitally recorded, transcribed and analysed using NVivo software.

<sup>8</sup> More information on the characteristics of the sample is given in Chapter 4. Information on the young carers projects is detailed in a table in Appendix One.

<sup>9</sup> <http://www.youngcarer.com/events-and-training/young-carers-festival>

<sup>10</sup> Ideally a longer gap between interviews would have been incorporated, but the short timeframe for the whole study did not allow for this.

## 1.2 Structure of the report

In the next chapter of the report, the context for the research is explained. The first section reviews literature relating to the needs of young carers, in particular the sub-groups identified in the research brief, alongside other research findings about service engagement with disadvantaged groups. Some information from the Census on the ethnic profile of young carers is also included, as well as developments in legislation and guidance related to young carers during the past two decades.

Chapter Three focuses on the first research question and looks at competing claims around the number of young carers and how these were generated. At the end of the chapter, a set of suggestions for how to improve measurement of the scale of young people's caring is put forward.

The fourth chapter of the report uses findings from the interviews to explore how young people experience caregiving responsibilities and the support they themselves had received. The sections in this chapter consider in detail what the young people conveyed about their lives, how they conceived and interpreted their role, what they

did as part of caregiving, what impact it had had on them, what had been helpful in the past, what can make engaging or working with professionals difficult, and how services could work in ways to better support young people in the future.

The fifth chapter draws together a number of different conclusions from the various elements of the study. It summarises key considerations around the support of young carers and their families. It also highlights the particular vulnerability of some young carers and their families relative to their individual circumstances, and how services need to be flexible in their responses to adequately meet the variety of needs that can be presented. Finally, there is a discussion of issues around the definition of young carers and the terminology in use, how these proved to be impediments to this study (and others), and have hindered the provision of services and support – leading to a suggestion that it may be timely to rethink how young people's caring is conceptualised, including both the objective and subjective parts of being a caregiver and particularly in relation to the most disadvantaged families.

## 2. Context for the research

This chapter offers an overview on what is currently known about young people's caring in order to contextualise this research.

Official data from the 2001 Census and the 2011 Census is presented to outline what this source of information has revealed about the numbers of young carers, their age and ethnicity, and changes in the overall profile of the young carer population over the 10 years between the two exercises.

Much research has been conducted into young people's caring. This chapter provides an overview of literature related to the particular aims of the study and also incorporates the findings from other research on how some

groups (eg BME families) are marginalised in terms of access and use of services.

Changes to legislation, guidance and policy related to young people's caregiving over the past 20 years are also described in this chapter, in order to explain the shifting context for direct support to young carers over time.

### 2.1 Official figures on young carers

Census questions about whether there were young carers in a household were asked for the first time in 2001, and again in the following wave of data in 2011, allowing for a review of changes in the numbers and characteristics between the two exercises. In this

section, data in relation to young people's caregiving is presented to show the profile of this group of children, young people and young adults, and how ages and ethnicities are represented within the different age groups.

#### The ages of young carers

Different approaches have been used to categorise 'young carers' within research, for example in the age range that equates to being a 'young adult carer'.<sup>11</sup> The Census data presented here is subdivided into four age bands: 5 to 9 years old, 10 to 15 years old, 16 to 19 years old and 20 to 24 years old:

**TABLE 1: Changes in the numbers of children and young people in the population, in the numbers and proportion of young carers recorded, and in the overall proportions of young carers by age group between the 2001 Census and 2011 Census**

Age group	2001			2011			% change	
	Overall population	Number of young carers	% of young carers	Overall population	Number of young carers	% of young carers	Overall population	% of young carers
5–9 years old	3,118,934	12,386	0.4%	2,970,186	20,744	0.7%	-5%	+67%
10–15 years old	3,812,511	78,026	2.0%	3,696,524	89,969	2.4%	-3%	+15%
16–19 years old	2,261,676	97,878	4.3%	2,490,524	116,694	4.7%	+10%	+19%
20–24 years old	2,805,853	135,961	4.8%	3,411,283	176,196	5.2%	+22%	+30%
All years (5–24)	11,998,974	324,251	2.7%	21,568,517	403,603	3.2%	+4.7%	+24%

Source: Census tables M205 CT0415, Office for National Statistics (ONS)

<sup>11</sup> The inclusion of young people over the age of 18 in these figures may seem confusing, since the legislation on young carers (see next section) refers to 'children' (ie those aged under 18). However, research studies have often focused on the plight of young people aged 18-plus and so it seemed appropriate for this section to also present figures for the young adult age group.

<sup>12</sup> ONS, 2015

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

As can be seen in Table 1 on the previous page, there has been an increase in the numbers of reported young carers in every age band, and the following aspects of changes by age band are particularly noteworthy:

- The proportion of reported carers in the youngest age group – aged 5 to 9 years – had increased substantially, relative to growth for other age groups.
- Movement in the size of the reported young carer population for younger young carers (those aged under 15) ran counter to the change in the overall population, rising by 75% from 0.4% of the age group to 0.7% of the age group.
- In the 10 years between the Censuses there had been an overall growth of 24% in the reported number of young carers (aged 5 to 24 years old) in the population, as compared to a 4.7% growth overall for the number of young people in this age group.

### **The ethnicities of young carers**

Information on the ethnicity of young carers aged under 20 from the 2001 and 2011 Censuses is presented in Table 2 on the following two pages and indicates that:

- There are differences in the proportions of young carers within different ethnic groups – eg in 2011, 1.8% of young people in families who categorised themselves as being 'White Other', as compared to 3.4% who said they were 'Caribbean'.
- An increase in the percentage of young carers between 2001 and 2011 was reported more frequently for 'White' and 'Mixed/Multiple Ethnic Groups' than 'Asian/Asian British' or 'Black/African/Caribbean/Black British' categories. In fact, the 'Asian/Asian British and Black/African/Caribbean/Black British' categories generally saw minimal change or a decline in the percentage of carers, apart from Caribbean households which reported an increase.

- Of those categories that showed percentage point increases in young carers by ethnic group, or within age bands, none of them were large (ie no changes over 1%). It is not clear from the available data whether the observed changes are real trends or natural variations in data.
- Of those categories that showed percentage point declines in young carers by ethnic group, or within age bands, few of them were large (ie no changes over 1%). The exceptions to this were within the 'Asian/Asian British' 16 to 19 years old category, with a 1.3 percentage point fall in young carers amongst 'Indian', a 2.4 percentage point fall in 'Pakistani' and a 3.8 percentage point fall in 'Bangladeshi'.

**TABLE 2: Percentage of young people aged 5 to 19 in each ethnic group who were recorded as being young carers in the 2001 and 2011 Census**

Ethnic group		Age	2001	2011
<b>ASIAN/ASIAN BRITISH</b>	<b>Indian</b>	5–9	0.5%	0.7%
		10–15	3.6%	2.9%
		16–19	7.6%	6.3%
		All	3.8%	3.0%
	<b>Pakistani</b>	5–9	0.4%	0.7%
		10–15	3.7%	2.7%
		16–19	9.3%	6.9%
		All	4.1%	2.9%
	<b>Bangladeshi</b>	5–9	0.6%	0.6%
		10–15	3.8%	2.4%
		16–19	10.4%	6.6%
		All	4.4%	2.7%
	<b>Other Asian</b>	5–9	0.4%	0.7%
		10–15	4.7%	2.0%
		16–19	10.9%	4.3%
		All	2.7%	2.2%
<b>BLACK/AFRICAN/ CARIBBEAN/ BLACK BRITISH</b>	<b>African</b>	5–9	0.4%	0.6%
		10–15	1.8%	1.7%
		16–19	4.7%	3.9%
		All	1.9%	1.8%
	<b>Caribbean</b>	5–9	0.4%	1.0%
		10–15	2.4%	3.3%
		16–19	5.2%	6.0%
		All	2.5%	3.4%
	<b>Other Black</b>	5–9	0.6%	1.0%
		10–15	1.2%	2.7%
		16–19	1.9%	5.5%
		All	2.7%	2.6%

'There's nobody is there – no one who can actually help?'

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**TABLE 2: Percentage of young people aged 5 to 19 in each ethnic group who were recorded as being young carers in the 2001 and 2011 Census**

Ethnic group		Age	2001	2011
MIXED/MULTIPLE ETHNIC GROUPS	White and Black Caribbean	5-9	0.4%	1.0%
		10-15	2.2%	3.1%
		16-19	5.1%	5.8%
		All	2.0%	3.1%
	White and Black African	5-9	0.6%	0.9%
		10-15	2.1%	2.8%
		16-19	5.8%	4.9%
		All	2.2%	2.4%
	White and Asian	5-9	0.4%	0.7%
		10-15	2.2%	2.6%
		16-19	4.9%	4.9%
		All	2.0%	2.3%
	Other	5-9	0.5%	1.0%
		10-15	2.3%	3.1%
		16-19	5.1%	5.8%
		All	2.3%	2.8%
WHITE	White British	5-9	0.4%	0.7%
		10-15	1.9%	2.4%
		16-19	3.9%	4.5%
		All	1.9%	2.5%
	White Irish	5-9	0.4%	0.9%
		10-15	2.4%	3.4%
		16-19	4.7%	5.4%
		All	2.5%	3.2%
	White Other	5-9	0.3%	0.5%
		10-15	1.9%	1.8%
		16-19	4.2%	4.0%
		All	1.9%	1.8%
OTHER	Other	5-9	0.2%	0.8%
		10-15	1.9%	2.5%
		16-19	4.8%	5.9%
		All	2.1%	2.7%

Source: ONS, 2015

Specifically considering older young people – those aged 20 to 24 years old – there was a mixed picture for how the proportions of young carers in each ethnic group had changed between 2001 and 2011 (see Table 3, next page):

- There was a decline in the percentage of young carers for all the groups within 'Asian/Asian British' households.
- The percentage of young people from 'White' families who were carers had increased, but not by more than one percentage point for any of the sub-categories.
- For young people of 'Black' or 'Mixed/Multiple' ethnicity there were variations by groups – ie some declines in the percentage of carers (eg for 'White and Black African' young people a fall of 0.7 percentage points) and some rises (eg for 'Caribbean' young people a rise of 0.9 percentage points).

As will be discussed in the following chapter, there are reasons to suggest that the methodology employed to collect Census data in relation to young people's caring is problematic in a number of ways. It is also important to bear in mind that the data from just two exercises

over a 10 year period does not give sufficient information to identify trends across the overall population. However, the information presented above offers one estimate of the scale and scope of young people's caregiving, which contributes to understanding of the phenomenon.

## 2.2 What is known about how the needs of young carers may be different according to their age or ethnicity?

### Age

Little is known about the specific needs of the youngest young carers – those aged 10 or less. Despite some studies reporting that the young people who took part felt they had 'always' been a carer, or were 'born into' their caregiving role (eg Hamilton, 2013; Cass et al, 2009), research to date has mainly focused on young people of secondary school age and above (Fives, 2013; Warren, 2008; Dearden and Becker, 2004).

Although some studies have small numbers of 'younger' participants within their samples (Cree, 2003; Warren, 2007) there is limited analysis of the particular needs

and experiences of this age group. An exception was a study of well-being and happiness in young carers (Lloyd, 2013) study of well-being and happiness in young carers – specifically looked at the roles and experiences of over 4,000 young carers aged 10 and 11 in Ireland. This research found that young carers of this age were more likely to have experienced bullying, enjoyed school less, and had slightly lower self-reported health and well-being scores than their peers who did not have a caregiving role at home.

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

**TABLE 3: Percentage of young people aged 20 to 24 in each ethnic group who were recorded as being young carers in the Census**

	2001	2011	Change
ASIAN/ASIAN BRITISH: Indian	8.5%	7.5%	↓
ASIAN/ASIAN BRITISH: Pakistani	11.3%	9.6%	↓
ASIAN/ASIAN BRITISH: Bangladeshi	13.7%	11.7%	↓
ASIAN/ASIAN BRITISH: Other Asian	11.8%	4.5%	↓
BLACK/AFRICAN/CARIBBEAN/BLACK BRITISH: African	5.4%	5.2%	↓
BLACK/AFRICAN/CARIBBEAN/BLACK BRITISH: Caribbean	6.1%	7.0%	↑
BLACK/AFRICAN/CARIBBEAN/BLACK BRITISH: Other Black	1.5%	7.2%	↑
MIXED/MULTIPLE ETHNIC GROUPS: White and Black Caribbean	6.1%	6.7%	↑
MIXED/MULTIPLE ETHNIC GROUPS: White and Black African	6.3%	5.6%	↓
MIXED/MULTIPLE ETHNIC GROUPS: White and Asian	5.5%	5.4%	↓
MIXED/MULTIPLE ETHNIC GROUPS: Other	5.3%	6.2%	↑
WHITE: British	4.4%	4.9%	↑
WHITE: Irish	3.8%	4.2%	↑
WHITE: Other	3.1%	3.2%	↑
OTHER	4.5%	6.5%	↑

Source: ONS, 2015

In recent years there has been a particular focus on 'young adult carers', a group which (perhaps confusingly) has been defined as including young people from 14 to 25 years old.

The primary focus in these studies has been on the transition from 'child' to 'adult', both in regard to life stage and development and in terms of the young person as an 'ageing' service user (eg Becker and Becker, 2008; Heyman, 2013; Becker and Sempik, 2013, 2014). Many of the reported experiences and support needs of young adult carers mirror those of young(er) carers in relation to education, social life, health and well-being – but there may be additional challenges for them because of their life stage and the impact of contemporary Western cultural norms for young adults which imply the need to explore new opportunities linked to burgeoning independence (eg leaving home to attend higher education courses, beginning training or work - Heyman and Heyman, 2013). Researchers have suggested that a young adult carer may feel conflicted because of these pressures, given their responsibilities at home (Dearden and Becker, 2000; Becker and Becker, 2008).

Others have made the point that, whilst assumptions about what is appropriate or expected at different ages or life stages may be subjective and culturally-relative, there are clear delineations in policy and legislation in England which can mean that young carers in receipt of specific support may be left without this once they turn 18 (Dearden and Becker, 2004; Becker and Becker, 2008).

### **Ethnicity**

Although much of the research literature on young carers does not report fully on the ethnicities of young people who took part, or look specifically at their experiences, some studies have specifically focussed on the experiences of BME young carers:

- A Joseph Rowntree Foundation-funded study published in 2002 researched a group of BME families who were using a BME-specific project for young carers (Jones et al, 2002).
- A small, qualitative study in 2003 looked at the experiences of 11 BME young carers in a generalist young carers service (Mills, 2003).

These two projects produced conflicting findings on how best to meet the needs of BME service

users. The first reported that participants 'spoke highly of the advantages of a separate project for black young people and their families'. In the second project, the majority of participants did not feel that a specific group for BME young carers was 'important or relevant', echoing findings from an earlier study (Shah and Hatton, 1999).

Despite this contrast, many of the broader issues highlighted were similar across both studies. BME young carers and their families were found to experience the same difficulties as their White British counterparts – but these could be further compounded by language barriers, bullying, racism and fear or lack of understanding of services. Research on how ethnicity affects perceptions or the take-up of other services (ie those not aimed at families where there is a specific caregiving need) and the degree to which services themselves are accessible or culturally-sensitive, may offer some clues as to the absence of BME young people in young carers services. These studies have demonstrated that:

- Some health conditions are more stigmatised in particular BME communities, and this may mean that support is

sought informally rather than through formal services, thus allowing people to avoid publicly disclosing information (Shah and Hatton, 2004; Hubert, 2006, Grey 2011).

- Although there may be cultural connections between people of the same ethnicity, alongside shared beliefs or needs, there is also likely to be extensive variation depending on location, poverty and deprivation levels, education, employment, distribution of services, closeness to family or community networks, immigration history, family structure, and personal preference (see for example Hirsch, 2011).

The broader implications of these issues for young carers services are discussed in the following section.

### 2.3 What is known about why young carers and their families do not access services?

Young carers have been conceptualised as a 'hard to reach' or 'hidden' group (Doutre, 2013; The Children's Society, 2013; Frank, 2002), and there is evidence that young people in caregiving roles are often overlooked by services and therefore do not feature in the data collected by, or the strategic thinking of, many mainstream services – for example one study found that only 0.6% of formal

carer assessments took place for young people aged under 18 (Buckner, 2013).

Research literature points to a multitude of factors that may hinder young people and their families from accessing support or services including:

- a lack of appropriate, accessible or affordable services for carers (Smyth et al, 2011; Cass et al, 2010; MacArthur, 2007; Olsen, 2000; Dearden and Becker, 2004)
- explicit or inadvertent exclusion from services (eg because of age restrictions, or cultural or language barriers) which can, in turn, result in fewer opportunities to find out about further support that may be available (Hirsch 2011).

Some researchers who have studied excluded groups in relation to other service provision have suggested that it is not the family or the individual that is 'hard to reach', but the ways that organisations or services themselves are structured, organised or operated which produce barriers to engagement (Boag-Munroe and Evangelou, 2010; Cortis, 2011).

On the basis of a systematic review of research on engagement by 'hard to reach' families with early years services, Boag-Munroe and Evangelou (2010) proposed a three-category typology of the reasons why families may not be identified as

being in need, or may not access services:

- organisational barriers (those which were not related to individual families, but about how services themselves operated)
- families as 'hard to reach' (where families did not know about services or were not able to engage with them)
- families as 'hard to engage' (where families did not want to access support or were wary of services).

This is instructive when considering the situation with young carers and their families, and the implications are explored later.

#### **Organisational barriers**

Many of the factors raised in the literature as to why young carers may remain 'hidden' or 'hard to reach' refer to issues related to how services are organised or administered. Boag-Munroe and Evangelou separated these issues into two themes: communication and setting.

#### **Communication**

A key concern is the way in which information about services and support is communicated. A number of studies identified that young people and their families are unlikely to recognise their caregiving role 'spontaneously' and so will not be looking for support, whilst others may fail to realise there are services

available to support them (Smyth et al, 2011; Hamilton, 2013). This may be due to their age, or other factors such as limited opportunities to spend time away from their caregiving commitments. As such, young carers may not know what support is available for them, particularly if information is not provided in an age-appropriate format, or if they are not given information due to a failure to recognise their role (McAndrew, 2007; McArthur, 2007). There is also evidence that professionals may fail to consult young people or keep them informed about the person they care for, even where they are the primary carer (Mills, 2003). This may be particularly true for younger carers (Hamilton, 2013).

This might be further compounded in situations where communication methods do not take into account language or fluency, illiteracy, disability (and communication needs), cultural beliefs or the understanding of service users. This can mean that people struggle to find information about the services which are available, in turn increasing their potential isolation, and may even render services completely inaccessible to them (Shah, Hatton et al, 2004; Hubert, 2006).

According to Census figures, 5% of the population of England live within households where no adults speak English as a main

language (ONS, 2013). Research has also highlighted how needs can be higher in families where English is not the first language (Mills, 2003), and how young people living in these households are also more likely to have a caregiving role (Hounsell, 2013).

The choice of terminology used to communicate with potential service users may act as a barrier to engagement with some young people. A number of studies have shown that some participants did not identify with the term 'young carer', but regarded their role simply as 'helping out' or being a 'helpful child', especially if they were not the primary carer in the household (Smyth, 2010; Mills 2003, Jones, 2002).

For others, the term 'young carer' felt synonymous with 'do-gooder, victim, or different' – which was not how they saw themselves. Many did not want to be viewed as 'victims' or 'angels' or 'heroes' (Jones, 2002; MacArthur, 2007). In addition the use of medical terminology has been identified as a barrier, preventing young people from being kept fully informed about the condition and needs of the person they cared for (Smyth et al, 2011; McAndrew, 2007).

### **Setting**

A number of studies note the difficulties of accessing services due to their location, cost or environment. The fee charged for using a service may be a

restrictive factor for many families (Hubert, 2006), as may the length of journey involved or the cost of transport (Hamilton, 2013; McArthur, 2007).

The literature also points to debates around whether being generalist or more targeted can contribute to the exclusion of some groups. Populations of people with specific needs may find 'mainstream support services inappropriate or difficult to access, whilst more targeted or specialised forms of help may feel stigmatising' – and, within 'hard to reach' groups there will be sub-groups that are particularly 'hard to engage' (Cortis, 2011). This echoes the two studies of BME carers mentioned previously (p15), one of which highlighted the value of BME-specific services, and the other reluctance that some BME families may have in using specific services (Jones, 2002; Mills, 2003).

Cultural insensitivities have also been reported as factors which can prevent or deter families from accessing care (Smyth et al, 2010; Manthorpe et al, 2008; Shah and Hatton, 1999), including:

- a lack of understanding of cultural needs including language, dress, etiquette, and routines (see for example Hubert, 2006; Shah, 2004)
- assumptions that every community will work in a uniform way – in particular, myths around certain

communities 'looking after their own' (Chahal and Uttah, 2004; Mills, 2003; Welsh Assembly, 2003). This is particularly problematic as research has also found that some BME carers can become isolated from any support because their familial or community networks have been reduced eg due to migration or the stigma of their condition – Shah, 1995; Mills, 2003; Hubert, 2006; Charles, 2010.

One report suggested that schools in particular varied in terms of the support they provided for young carers, the level of awareness among teachers of what support was available, and the degree of effort used to identify carers amongst pupils (Barnados, 2006). Others have noted that the lack of flexibility among schools in their responses to young people's caregiving responsibilities could become problematic in relation to their participation in education, as 'caregiving always came first' (Hamilton, 2013).

High turnover of staff within services – with the knock-on effect of a loss of knowledge of the situations of individuals or families – can also deter service users from accessing services due to a reticence towards having to repeatedly retell different staff about sensitive, personal information (Boag-Munroe and Evangelou, 2010). And poor experiences of service delivery –

long waits, administrative errors, lack of resources, unfriendly or unwelcoming environments – can discourage families from using services again in the future, or deter other members in the same community from approaching services (MacArthur, 2007).

### **Families as 'hard to reach'**

Boag-Munroe and Evangelou identified barriers which prevented families from accessing support – ranging from lack of awareness of service availability to constraints linked to physical health or disabilities.

Analysis of Census data<sup>13</sup> has indicated a correlation between increasing hours spent caregiving and worsening physical health, and analysis of the Longitudinal Survey of Young People in Education (LSYPE) data revealed that young carers were 1.5 times more likely to have a special educational need or disability (The Children's Society, 2013). Both of these findings suggest that some young carers and their families will have particular needs that services will have to take into account in promoting accessibility and responding well.

Other research has provided additional evidence that young carers may be more likely to have physical or mental health problems (related to caregiving or otherwise) than their non-carer peers, inhibiting their ability to access services and support – eg Tunnard, 2001; Cree, 2003; Hill, 1999; Waters and Rigby, 2008.

Research has also suggested that young carers may be 'time poor' (eg in relation to having a social life outside home, or any engagement in activities outside the home) because of the need to prioritise their caregiving responsibilities (Hamilton, 2013; Tatum, 1999). Another contributory factor to this likelihood of social isolation is young carers' feelings of being 'different' from other young people (MacArthur, 2007; Butler and Astbury, 2005). Both of these factors could restrict young carers' ability or desire to access services.

Other social factors may contribute to young people and families not being in a position to access services provided for them. Poverty in particular can contribute to involuntary isolation if this means that transport or other costs associated with using a service cannot be covered – and this may be a pertinent factor for BME communities where levels of deprivation, including in-work poverty, are high (Barnard and Turner, 2011). Likewise, being new to a country may contribute to heightened caregiving needs within a family. Lack of knowledge or understanding of systems for support may hinder access to care and, in some cases, immigration issues may form part of the background to a young person's caregiving role (Jones, 2002). Furthermore, people's immigration histories or social isolation relating to their immigration may complicate, or

be the reason for, their care needs (Charles, 2010).

### **Families as 'hard to engage'**

The final category used by Boag-Munroe and Evangelou summarised the factors which make it difficult for services to engage potential service users because they choose to 'voluntarily' isolate themselves, have reservations about using a service, or are wary of possible 'consequences'.

Research on young carers has found that some families make a choice to avoid or refuse external support. They may feel uncomfortable about 'strangers' providing care (Hirsch, 2011; Hubert, 2006), believe that caregiving should be carried out by family members (Bell and Casebourne, 2011; Smyth, Blaxland, Cass, 2011), or consider caregiving roles to be 'normal household chores' (Warren, 2007).

Families may also choose to remain silent due to the stigma of their situation (Smyth et al, 2010; Aldridge and Becker, 2003; Shefer et al, 2012) and due to fear of the response from services (Fives, 2013; Smyth, Blaxland and Cass, 2011), members of their community (IRISS, 2010) or their peers (MacArthur, 2007). Alternatively, they might view certain conditions and illnesses as an inevitable part of ageing, and therefore not seek help (Pocklington Trust, 2008).

For some families, reservations may occur due to concern about a service being insensitive to cultural beliefs or requirements (Hirsch, 2011). And some may be wary of disclosing a caregiving role for fear of being judged or viewed negatively, or that this could lead to child protection interventions and family breakup (Fives, 2013; Jones, 2002).

Evidence that some families'

concerns about this may be legitimate came through Dearden and Becker's research, published in 2004, which found that BME young carers were nearly twice as likely to have received an assessment under the Children Act (21% compared to 11%) – suggesting a bias in the way different families are perceived by professionals.

Bad experiences with services – or knowledge of the bad experiences of others within a family or a community – can also be a deterrent to seeking support from organisations or agencies (Jones, 2002; Pocklington Trust, 2008). And families may feel angry, frustrated or unable to communicate with those who might help, or feel that involvement will not bring about positive changes (MacArthur, 2007).

### **Key Points**

Little research has been done into the needs of carers of primary school age. Research on young adult carers indicates that there are challenges for this group in terms of life stage and transition. Though some studies have contested this as relating principally to the cultural norms of only some young people, there is evidence that services and support may become less available as young people approach 18.

Data from the two most recent Censuses has suggested that overrepresentation of BME groups amongst young carers has reduced overall, but for older young people – aged between 16 and 24 – those of Asian origin were much more likely to have a caregiving role at home. Cultural factors for different minority ethnic groups can affect the take-up of support services by families, leading to an increased reliance on caregiving capacity within the household. Whilst some literature suggests that research has suggested that there may be little difference between the experiences of white and BME young carers.

A typology of the factors affecting service access has been developed – indicating that 'organisational barriers' (linked to 'communication' issues or the 'settings' for service provision) can hinder service use, and that there are identifiable issues related to families being 'hard to reach' and/or 'hard to engage'.

## 2.4 Developments in legislation and guidance

This section of the report summarises changes in the key policies, legislation and guidance relating to support for young carers and their families in the UK over the last 20 years. In particular, it explains developments within children's legislation as well as in adults' health and social care guidance that have improved the context for support for young carers, culminating in the new Care Act 2014 and Children and Families Act 2014, which took effect in April 2015.

### Defining young carers within the law

As discussed later in the report<sup>14</sup> defining young carers has been a challenge for researchers and policymakers for many years. The Carers (Recognition and Services) Act 1995 offered a legal definition for the first time – defining young carers as 'children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis'. The same legislation gave all informal carers an entitlement to an assessment of their needs, separately from the needs of the person for whom they were caring.

There is still an ongoing debate regarding how the parameters of a definition should be set, but the

current 'official' definition<sup>15</sup> used in the new Care Act 2014 and Children and Families Act (2014) states that a young carer is:

*'...a person under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work).'*<sup>16</sup>

### Responsibilities of local authorities towards young carers: a changing focus over two decades

A gradual shift in the focus of local authority support for young carers has occurred since the Carers (Recognition and Services) Act 1995. This legislation recognised the existence of young carers and offered assessments and support – but separately from the person for whom they were caring.<sup>17</sup> This approach to meeting need has been subject to revisions over time, which have increasingly recognised the possible interdependencies within a family and proposed a focus on holistically assessing and meeting the whole family's needs. The 1995 Act included a requirement that families

themselves make a request for an assessment of need to take place – and this proved to be a significant obstacle to improving the situation for many young carers. The implicit expectation that families would acknowledge and report the caring status of their children was unfounded, resulting in many young carers remaining unidentified and unsupported by service providers.

Moves to replace this dependence on the family to instigate a process began with the publication in 1999 of a national guidance document, *Caring About Carers*,<sup>18</sup> which advocated a multi-agency approach for supporting young carers, taking into account the context within their family. The strategy emphasised that even with an adequate care package in place for the person with identified care needs, there may still be negative impacts upon children in the household. It called for improved recognition of the diversity of roles and responsibilities children may carry out within a family, alongside an acknowledgement of the potential detriments to their own well-being of taking on a caregiving role. This approach was mirrored in wider guidance to local authorities and health authorities around holistic assessment as the basis for effective support for 'children

<sup>14</sup> In Chapter Three (see pp 24)

<sup>15</sup> First published in a memorandum of understanding by the Association of Directors of Children's Services (ADCS) and the Association of Directors of Adult Social Services (ADASS) with the support of The Children's Society in 2009.

<sup>16</sup> nb The memorandum 'No Wrong Doors' – which also applies to young adult carers up to 25 – qualifies this to state that this relates to care for any family member who is physically or mentally ill, frail, elderly, disabled or misuses alcohol or substances (ADCS et al, 2015).

<sup>17</sup> Department of Health, 1996.

<sup>18</sup> Department of Health, 1999.

in need', issued as part of the 'Quality Protects' programme by the Department of Health, Department for Education and Employment and the Home Office in 2000.<sup>19</sup> Caring About Carers was quickly followed by the Carers and Disabled Children Act 2000, which gave carers aged 16 and over an entitlement to an assessment of their needs.

In 2004 two new Acts came into force that had positive implications for the recognition and support of young carers: The Children Act 2004 and the Carers (Equal Opportunities) Act 2004. Section 11 of The Children Act 2004 placed a statutory duty on key agencies, including local authorities, to make arrangements to safeguard and promote the welfare of children. The overall aim of this legislation was to encourage integrated planning, commissioning and delivery of services, as well as improved multi-agency working, increased accountability and better coordination within local authorities.

The Children Act also provided the legal underpinning for Every Child Matters (ECM)<sup>20</sup> which specifically identified young carers and their families as being likely to benefit from targeted, sensitive help through implementation of

the 'Maximising Opportunities and Minimising Risk' vision for children's services.<sup>21</sup> This emphasised the need to support families, to intervene earlier through better information sharing and a common assessment framework, for clear lines of accountability, and for children and young people to be involved in the design and delivery of services.

The Carers (Equal Opportunities) Act 2004 introduced a statutory obligation on social services departments to inform carers of their right to an assessment, and required that such assessments should consider whether the carer was working, wished to work or (more pertinently for young carers) wished to undertake education, training or leisure activities.

Practice guidance for this Act outlined the importance of considering the needs of the whole family. It stressed that young carers should be supported to 'prevent or reduce inappropriate or harmful levels of caring'. Service providers were urged to focus on meeting the needs of the adult using a 'whole family approach' – ie ensuring that the assessments and delivery of care for them was linked to the context within their household. The guidance was explicit that

no care package should rely on 'inappropriate' caring provided by a child.<sup>22</sup>

The guidance also directed local authorities to ensure that they had a multi-agency strategy in place to address the needs of young carers, and a shared protocol for adults and children's services for identifying and assessing young carers. It acknowledged that identification of young carers could be problematic, and that this may result in a lack of support. Particular contexts where this would be more likely were highlighted – eg in households where the person cared for was affected by mental ill health. The 2004 guidance also stated that in many cases families fear professional intervention and may be concerned about the stigmatisation of being assessed under children's legislation.

Through these pieces of legislation there was an emerging recognition that children should be protected from onerous caring roles at home. However the Acts placed no duty upon the local authority to provide support beyond an assessment of need – and a joint working exemplar protocol (legislated for in the 2004 Act) was not issued until 2009, with the development of a Memorandum of Understanding.<sup>23</sup>

<sup>19</sup> Department of Health, 2000.

<sup>20</sup> HM Government, 2003.

<sup>21</sup> Contained within the 'Next Steps' Government response to consultation on ECM, published in 2004.

<sup>22</sup> Social Care Institute for Excellence, 2005.

<sup>23</sup> By the ADCS, ADASS and The Children's Society. This was later updated in 2012.

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

This offered a firm basis for children's and adults' services to work together and in partnership with health and third sector organisations. The central issues outlined for young carers were:

- recognition of their needs
- adverse impacts upon their well-being
- the need to provide them with empowerment and support, including emotional support and accountability
- to consider need in the context of the whole family and joint working between adult and children's services.

### **The prevention of 'inappropriate care' by children and an emphasis on early intervention**

The idea of 'inappropriate' levels of caregiving by a child was first included in guidance to practitioners as early as 1998,<sup>23</sup> and government-sponsored strategies for carers have continued to use this term to underpin a commitment to support. For example, in introducing its 2008 strategy, the Department of Health stated that:

*'Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.'*<sup>25</sup>

and this was echoed in a refresh to the strategy in 2010:

*'Children and young people should be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.'*

Attempts to codify the meaning of 'inappropriate' care have been made on a number of occasions – for example, guidance in 2008<sup>26</sup> proposed an individualised approach to assessment of risk:

*'A young person becomes vulnerable when the level of caregiving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances.'*

The emphasis on recognising and preventing inappropriate caregiving by young people was paralleled in developments across safeguarding practice with an increasing onus on early intervention. For example, the Working Together to Safeguard Children<sup>27</sup> guidance published in 2013 set out how organisations and individuals should collaborate to enhance safeguarding and promote the welfare of children, and how practitioners should endeavour to improve standardisation in identification, assessment and provision of joined-up support.

<sup>24</sup> In the 'Framework for Assessment' (Department of Health, 2000) which stated that 'Young carers should not be expected to carry inappropriate levels of caring which can have an adverse impact on their development and life chances.'

<sup>25</sup> Department of Health, 2008.

<sup>26</sup> Frank and McLarnon, 2008.

<sup>27</sup> Department for Education, 2013.

## The situation in 2015

Over 20 years, developments in policy, guidance and legislation to define and protect young carers, and to improve assessment and collaborative working across agencies, have been consolidated through the implementation of the Care Act 2014 and Children and Families Act 2014, which require local authorities to take into account the needs of families as a whole.

*People should be considered in the context of their families and support networks, not just as isolated individuals with needs. Local authorities should take into account the impact of an individual's need on those who support them, and take steps to help others access information or support.<sup>28</sup>*

In addition, The Care and Support (Assessment) Regulations 2014 require local authorities to consider the impact upon carers (including children) when looking at the needs of the whole family:

- They must assess the point at which the amount of care and support that a child is giving may become 'excessive' or 'inappropriate' – when it could make them vulnerable to negative impacts upon their education, emotional or physical health and well-being.
- They should consider how the provision of support for the individual with needs can help prevent young carers from undertaking 'excessive' or 'inappropriate care'.

Under the new legislation all responsibilities for identifying and supporting carers (of any age) are placed with the local authority – and the requirement that a young person had to be providing a 'significant amount of care' before being eligible to receive an assessment has been removed. The changes also place a duty on local authorities to take 'reasonable steps' to identify young carers – with a fresh directive to be proactive in relation to this, to publicise and disseminate information about the support available, and to introduce preventative measures to reduce potential need in the future.<sup>29</sup>

## Summary

The position and rights of young carers and their families have improved in the past two decades. Early legislation which first acknowledged and provided a (limited) definition of a 'young carer' and provided for an individual assessment of need – but only at the request of a family – has been updated over time. It is now at a position where families have an explicit entitlement to a holistic assessment of need across all members, with a clear directive that the impact of caring should not be 'excessive' or 'inappropriate' for a young person, and that integrated services should be provided by local authorities to mitigate this, as well as to adequately look after the person whose condition requires care. Local authorities have also been mandated to prioritise early intervention and to ensure that the welfare of young people who are young carers is protected.

<sup>28</sup> Paragraph 1.14 (f) Care and Support Statutory Guidance (Issued under the Care Act, Department of Health, 2014)

<sup>29</sup> More detailed information on the obligations under the Act are given in new guidance (see Appendix Three), The Young Carers (Needs Assessment) Regulations, 2015, and in 'Working Together to Safeguard Children', Department for Education, 2015.

### 3. How many young carers are there? Competing claims and suggestions for how to measure

The 2011 Census found that there were 166,363 young carers aged 5 to 17 years old in England, an almost 20% increase from the figure in the 2001 Census.<sup>30</sup>

The current research was initially conceived in response to this and other headline findings from what is generally regarded as the most authoritative and accurate dataset on how we live in the UK today.

At the time the research was commissioned it was apparent that there was burgeoning interest in the scale of young people's caregiving among policymakers in England, not least because fresh legislation was in the pipeline around the responsibilities of local authorities to better assess and respond to the needs of carers within families, with a concomitant requirement to understand the true scale of caregiving by young people in every community.

The first aim for the study – as described in the original brief put together by the Young Carers in Focus programme<sup>31</sup> and the Big Lottery Fund – was to:

*'Better understand why there has been an increase in the number of young carers identified' (in the 2011 Census).*

However, initial scrutiny of the Census methodology by the researchers who had been asked to undertake the study indicated that there could be issues in relation to the accuracy of figures that had been generated on young carers.<sup>32</sup>

A further exercise reviewing other research on young carers found that there were many alternative estimates of the scale of caregiving by young people across the UK, including a relatively recent BBC-commissioned study (BBC/ University of Nottingham, 2010), which had suggested there were around 700,000 young carers (more than four times the Census figure), and analysis of data from the Longitudinal Study of Young People in England (The Children's Society, 2013) which proposed a figure of 25,000 for young carers in school Year 9 alone (ie among young people aged 13 to 14).

At this point it became clear that it would not be feasible to authoritatively answer the research questions being posed around prevalence and change within the bounds of this study, and so it was agreed that the best course of action for the first element would be to look at how and in what contexts prevalence of caregiving had been estimated before, to consider the figures

and the legacy from these studies, and to offer ideas for a more appropriate methodology for future estimation.

This section of the report gives a brief critique of the Census methodology and of research over the past 20 years which has put forward estimates for the numbers of young carers. It also outlines some ways in which future exercises could be improved to measure both the objective elements of caregiving and to reflect the associated impact on the young person who cares, now understood to be fundamental in assessing the status of 'young carer'.

The discussion presented here does not claim to be based on an exhaustive review of the literature on this issue, nor does it extend beyond UK research. However, every reasonable effort was made to incorporate key studies and to consider associated developments in policy, legislation and guidance – the context within which estimates have been made – as a way of interpreting the varying findings on the scale of young people's caregiving that were produced at different points in time.

<sup>30</sup> <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html>

<sup>31</sup> The Young Carers in Focus (YCiF) Programme is funded by the Big Lottery Fund and led by The Children's Society. This four year programme is establishing a national network of young carers, enabling them to communicate, share stories and campaign for the things that matter the most to them. (<http://www.childrensociety.org.uk/what-we-do/helping-children/young-carers/young-carers-focus>)

<sup>32</sup> An issue picked up in other research on young carers – eg Becker (2007)

### 3.1 Defining 'young people's caregiving'

In order to review the research which has estimated the scale of young people's caregiving, it is important to firstly consider the issue of definition. Without being clear on what is being counted it is difficult – as researchers on this topic have found – to know how best to collect data, to analyse and interpret.

The 1995 Carers (Recognition and Services) Act specified that a carer was someone who provided, or intended to provide, a substantial amount of care on a regular basis, and that this equally applied to children and young people under 18 who took on a caregiving role. The Act also specified that the person receiving care may or may not be a relative and may or may not live in the same household as the carer.

According to the Blackwell Encyclopaedia of Social Work (Becker, 2000), young carers are:

*Children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant*

*or substantial caregiving tasks and assume a level of responsibility, which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.*

This definition includes an implicit acknowledgement that there are circumstances where a young person has a caregiving role within their family, which could be 'irregular', 'insignificant' or 'insubstantial' – and may perhaps be positive.<sup>33</sup> These young people should not, therefore, incur the label 'young carer', which was intended to be a marker for problematic levels of caregiving responsibility.

This definition also flags the issues which have led to the difficulties in estimating the level of young people's caregiving. Where should the thresholds of acceptability be set for a child or young person – who may be any age up to 17<sup>34</sup> – for frequency,

amount and types of care, and level of responsibility? And some elements of this definition are contrary to that in the 1995 Carers Act, as this clearly states that the cared-for person is 'another family member'. So what should the criteria be to guide an estimation of the scale of young people's caregiving?

Debates about this continued – and research studies proceeded – until 2008, when guidance to professionals (Frank and McLarnon, 2008) who might work with young carers included the following sentence, qualifying the prior definition:

*A young carer becomes vulnerable when the level of caregiving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her physical well-being or educational achievement and life chances.*

This was indicative of an increasing desire (at the time principally among specialist practitioners in voluntary sector projects) to improve how young carers were assessed

<sup>33</sup> As some research has demonstrated, having a caring responsibility can have positive benefits for many young people (Joseph, Knibbs and Hobbs, 2007; Evans and Becker, 2009).

<sup>34</sup> Findings from the Census were reported for 5 to 17 year olds, and some research has suggested that there are very few young carers under the age of five (eg Dearden and Becker, 2004) – though it is difficult to say conclusively whether a younger child could be a young carer. Many participants in this study said they could not remember when their caring role had started.

and to encapsulate the volume and frequency aspects of care alongside the more individualised impacts their role may have on a young person. This culminated in the creation of a joint memorandum of understanding between the Association of Directors of Children's Services, the Association of Directors of Adult Social Services and The Children's Society in 2012 – which included a refreshed definition:

*The term young carer should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances... A young carer becomes vulnerable when the level of caregiving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances.*

This explicit inclusion of caregiving for those who were misusing substances clarified a position that was not apparent in previous definitions – where the onus had been on physical health difficulties linked to disability or old age, or on mental ill health. And the personalisation element of the definition, linking caregiving to negative impacts, was also extended at this point to include 'emotional' as well as 'physical' well-being.

At the same time the legal definition remained unchanged and the new 2014 Care Act and Children and Families Act is underpinned by the same basic statement on what constitutes a young carer as the 1995 Act. However, it is apparent that the way in which being a 'young carer' has been regarded and conceptualised has changed during the course of the last 20 years – and that this has led to problems for researchers in their efforts to measure the scale of the phenomenon.

### 3.2 Estimating the number of young carers – figures from research

The earliest research studies on young carers were published in the late 1980s, when it was believed that young people's caregiving was a relatively rare occurrence (O'Neill, 1988; Page, 1988). In 1992, Parker's analysis of the 1985 General

Household Survey provided an early estimate of the scale of the issue, reporting that 17% of carers aged 16 to 35 had been caregiving since before their 16th birthday – which suggested that as many as 212,000 adult carers had been young carers during their childhoods. In 1995, in an evaluation of three young carer projects, Mahon and Higgins estimated the figure was somewhere between 15,000 and 40,000 (Aldridge and Becker, 2002).

In an attempt to generate a more accurate estimate, the Office for Population Census and Surveys (OPCS; now the Office of National Statistics or ONS) included questions in the 1994/1995 OPCS Omnibus (Walker, 1996) to identify households with a young carer. This was defined as a person aged between 8 and 17 who 'looked after or gave special help to someone living in a household who was sick, handicapped [sic] or elderly'. From 12,000 households, this identified 78 in which there was potentially a young carer. After applying exclusion criteria – those caregiving for less than 10 hours a week where they were not the only carer, and those who were the only carer but spent less than five hours on 'fairly minor' types of care – 29 households remained. From these, the Omnibus interviews identified 18 'young carers', less than half a percent of the nearly 4,000 young people in the overall sample of

families. Using this proportion, Walker suggested that there were between 19,000 and 51,000 young carers – with a mid-range estimate of 32,000 – in the UK population.

Walker's estimate – whilst being the first to be based on a sophisticated methodology and systematic process to select out 'spurious' cases – would have omitted a cohort of young people who would now fall into the definition of 'young carer' (eg due to the exclusion criteria used which primarily concentrated on number of hours spent caregiving). Walker also noted that non-participation in the survey (which was a voluntary exercise) may have disproportionately impacted on the number of young carers identified, and concluded that as many as an extra 7,500 may need to be added to the mid-range estimate to provide a more accurate overall figure.

Other researchers extrapolated figures for each country within the UK from Walker's estimates – for England nearly 27,700 young carers; for Scotland 3,000; Wales 1,700 and Northern Ireland 1,200 – though they argued that the higher end of Walker's estimate range might be the more accurate figure, especially because official rates for disability were higher outside England (Baldwin and Hirst, 2002).

In 1999 the Scottish Household Survey – using a different methodology and a new definition – concluded that there were 6,000 young people in Scotland under the age of 16 providing informal care (Scottish Executive, 2001), double the figure derived from Walker's overall estimate. In the same year it was announced by the UK Government – as part of a new National Carers Strategy (Department of Health, 1999) – that a question would be included for the first time in the 2001 Census to ask about caregiving, particularly aimed at finding out more about the caregiving roles of young and BME people.

This development was a watershed, promising a significant shift in the accuracy of estimates for young people's caregiving, and was warmly welcomed by the charities and interest groups which had begun to emerge in response to increasing societal recognition of the issues and the importance of better addressing the needs of young carers.<sup>35</sup>

The 2001 Census recorded a total of 139,199 young people in England aged 5 to 17 (1.7%) who were carrying out a caregiving role (ONS, 2003). Of these, 134,116 were aged between 8 and 17 – a number four times greater than Walker's mid-range estimate five years earlier. However, as will be discussed below, there is ample reason to question the veracity of this figure.

Over the next decade, at least five estimates were produced of the numbers or proportions of young carers. The first of these was derived from a survey conducted with school pupils in a Social Inclusion Partnership area in Scotland (Banks, 2001). Of the 506 respondents (aged 11 to 17), 23% reported that they had a caregiving role, but only 6% because of an illness or disability, and 3% who spent seven or more hours a week on those tasks.

The second was generated from a wider research study (Cawson, 2002), the NSPCC's Child Maltreatment Survey, which found that of 2,869 respondents aged 18 to 24, 4% reported that they had cared regularly for a family member at some point before they were 18 years old. Using Census figures, Cawson extrapolated that 165,000 young people aged 18 to 24 had cared for a family member at some point during their childhood.

The third study was the Longitudinal Survey of Young People in England (LSYPE). This panel survey – coordinated by the Department of Health with a nationally-representative sample of 15,500 young people – began in 2004, when the cohort were in Year 9 at school, and has since revisited the group on regular occasions to ask questions about how their lives are changing over time. Alongside a range of questions around family, the first wave of the survey asked about

<sup>35</sup> For example, The Children's Society founded some of the first young carers projects in Hampshire in 1995.

caregiving responsibilities in the home, and, where a young person indicated that they were caregiving, additional questions on whom they looked after, for how many hours per week, whether they had ever missed school because of caregiving responsibilities and (if they had) how often.

Analysis of the dataset (Hounsell, 2013) found that 4.5% of 13 to 14 year olds (which would equate to 25,000 young carers in this age group across the country) were caregiving for a family member. There was no significant difference for the gender of those providing care, but there was higher prevalence in some ethnic groups eg 10% of Indian respondents had a caregiving role, compared to 4% of White British.

The fourth research study in 2005 (Warren) compared the roles of caregiving and non-caregiving young people. Fieldwork was conducted in one unitary authority, through structured interviews with a randomly selected sample of young people aged 9 to 18 in 'public areas' (eg youth clubs, a shopping centre, near schools), supplemented by a targeted sample of 12 young people already identified as carers. One of the findings from this study was that of the 378 young people interviewed who had not previously been attributed the status of 'young

carer', 9% (59% girls, 41% boys) were undertaking caregiving tasks sufficiently frequently that they might legitimately be given the label. Of this group – which the paper described as 'hidden' carers – 59% were BME, despite being only 25% of the sample.

Warren argued that this suggests there could be up to 600,000 BME young carers in the UK.

The fifth estimate, published in 2010 and based on a survey commissioned by the BBC and conducted by researchers at the University of Nottingham, used a tool which had been created to measure caregiving responsibilities of young carers (the MACA – YC18), which asks about different types of care ('domestic tasks', 'household management', 'personal care', 'emotional care', 'sibling care' and 'financial/practical care') and frequency of undertaking tasks (Joseph et al, 2008). The tool was deployed in a survey of secondary school pupils across the UK. A total of 4,029 students took part and it was reported that 20% of them were found to be helping out considerably at home, with 29% providing 'emotional care'.

By taking 'personal care' (which included the items: 'Help the person you care for to dress or undress', 'Help the person you care for to have a wash' and 'Help the person you care for to have a bath or shower') as the primary

indicator for being a young carer, the researchers suggested that 8% of students reported providing this type of care at least some of the time, and, by cross-referencing with population data from the 2001 Census, calculated a figure of 700,000 young carers for the UK.<sup>36</sup>

Between 2001 and 2011 then, sandwiched between the two Censuses, five estimates of the number of young carers were published:

- 165,000 in the UK – retrospectively assessed from 18 to 24 year olds (Cawson, 2002)
- Between 3% and 6% of 11 to 17 year olds in Scotland (Banks, 2005)
- 4.5%/25,000 of 13 to 14 year olds in England (LSYPE – 2004, analysis in The Children's Society, 2013)
- 9%/up to 1,050,000 of 9 to 18 year olds in England (Warren, 2005)
- 8%/700,000 of 5 to 18 year olds in the UK (BBC/ University of Nottingham, 2008)

<sup>36</sup> [http://www.bbc.co.uk/pressoffice/pressreleases/stories/2010/11\\_november/16/carers.shtml](http://www.bbc.co.uk/pressoffice/pressreleases/stories/2010/11_november/16/carers.shtml)

<sup>37</sup> This research was principally designed to explore issues around child maltreatment, so it is likely that less consideration was given to ensuring that the data would provide an accurate estimate of the prevalence of young people's caring.

The huge variation across these estimates has added confusion to an already contested issue – and suggests that there are limitations in the methodologies used. Some of these are:

- Cawson's research – though this offered an insight into the scale of young people's caregiving, the dataset did not cover the ages of respondents when they were caregiving, time spent or tasks undertaken, preventing a more sophisticated analysis of the nature of the caregiving roles being undertaken.<sup>37</sup>
- Banks' study – was based on a 5% sample of young people in an area with a high level of poverty and ill health, factors which may have led to a higher estimate and which would suggest these proportions may not be applicable to a larger population. A similar challenge could be made to Warren's figures, which were based on data from an urban area with high levels of deprivation. Employing proportions from research which had used samples not representative of the whole population would be very unlikely to generate an accurate national picture.
- The Warren study – used an innovative approach to sampling in a bid to 'find' young people who were unidentified carers, but this approach may also have omitted young people who did

not appear to be within the prescribed age range for an interview, ie the recruitment process inadvertently led to researchers approaching young people to take part whom they were confident would be within range and, thereby, to excluding those who looked younger or older (which may explain why the most commonly reported age for respondents was 11 to 15). Ironically, there may also have been an underrepresentation of young carers because, as other research has underlined (Frank, 1999; Halpenny and Gilligan, 2004), young people with caregiving responsibilities may be more socially isolated than their peers.

- The LSYPE survey – may not have adequately screened out young people whose caregiving responsibilities would not have met the key criteria for being a 'young carer'. The question asked was:

*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 someone who lives here with you that you have to look after on a regular basis?*

This wording – with an 'or' after the list of people within the household who might be cared for – meant that every teenager who looked after a younger sibling, regardless of the reasons for this and even on an occasional 'babysitting basis', could legitimately say 'yes' to the question. Further analysis of the data around whom respondents had cared for (for over 50% it was indeed a brother or sister – in contrast to research directly with young carers which has suggested that less than a third looked after a sibling, and that two-thirds cared for a parent<sup>38</sup>) and how much caregiving they did each week (on average three hours), suggested that the figure was likely to be an overestimate if referenced to the accepted definition of young carer.<sup>39</sup>

- Similar issues are likely to have been present with the 2008 BBC/University of Nottingham survey – though a full paper on the methodology for this has never been made available, despite it being widely quoted and used to promote the issue of young carers.

In the wake of these estimates the 2011 Census was conducted and a refreshed figure for young carers – of 166,363 – was produced, triggering concerns around an apparent increase in the numbers of children who were performing a caregiving role.

<sup>38</sup> eg see Dearden and Becker, 2004.

<sup>39</sup> There were young people in the sample who may well have met the criteria – eg 1 in 20 caring for over 15 hours a week and a similar proportion who had missed school because of this – but this subgroup have not been identified within the wider cohort.

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

### 3.3 Estimating the number of young carers – figures from Censuses

Figures derived from the 2001 Census and the 2011 Census datasets showed a rise in the proportion of young carers in the population of England from 1.7% of 5 to 17 year olds to 2.1% of same group. But how clear and accurate a picture of the scale of young people's caregiving did this give?

There are a number of potential problems with how the Census data had been collected. The question used was:

**Do you look after, or give help or support to family members, friends, neighbours or others because of either:**

- **Long-term physical or mental ill health/disability?**
- **Problems related to old age?**

It featured in sections intended to be completed by each individual household member. The response categories were:

- No**
- Yes, 1–19 hours a week**
- Yes, 20–49 hours a week**
- Yes, 50 or more hours a week**

It is perhaps important to understand that this question was designed to be multi-purpose – an attempt to capture data around 'unpaid caregiving' generally and linked to a heavily-promoted new national strategy on care sponsored by

Tony Blair early in his tenure as Prime Minister. Young carers were a relatively small part of this agenda, and perhaps a less politically important one. (As the terminology used in the strategy documentation underlines, 'unpaid care' is not generally a key part of the discourse around young carers, though it is closely associated with debates on the care that adults provide to other adults or their own disabled children).

Some of the issues that might undermine the Census methodology in terms of its ability to generate an accurate estimate of young people's caregiving are:

- The question phrasing does not prompt towards considering all the contexts where a caregiving role may ensue for a young person – eg where a parent is a substance misuser.
- There is much room for interpretation – or non-identification – of unpaid caring' tasks: '...look after, or give help or support' may be difficult to quantify, especially if the caregiving is done piecemeal across different days. And, for example, respondents may not associate tasks linked to emotional types of support (eg keeping someone company) as being caregiving.

- Responsibility for Census completion rests solely with the 'householder': The householder is the person who lives, or is present, at this address who owns/ rents (or jointly owns/rents) the accommodation; and/ or is responsible (or jointly responsible) for paying the household bills and expenses.<sup>40</sup> The householder can be prosecuted for non-response and fined up to £1,000. Whether or not, as was intended, any children in a household completed their own individual section is impossible to know – but it is perhaps unlikely for many, especially younger children. This means that the responses to this question will have come from different sources with different perspectives or knowledge of the amount of caregiving a young person may have done (and may in some cases have been provided by a respondent who wished to obscure knowledge of the presence of a young carer in a household – eg if this was arising due to misuse of illegal drugs).
- The response categories offer very broad time bands, perhaps because of the wider context within which the question was developed (ie it was intended to capture data around 'unpaid caregiving')

<sup>40</sup> From the Census 2011 questionnaire.

generally). This prevents more detailed analysis of smaller amounts of caregiving provided – an issue which has featured regularly in research and debates on being a young carer.<sup>41</sup> Also, as explained previously, although much of the data will have been provided by an adult 'householder', in situations where a young person had completed the section on this by her/himself it is unlikely that she/he would have known how many hours per week had been spent on caregiving. In this study – as is explained in more detail later – all the young carers who were interviewed were also asked to provide information on a self-completion questionnaire. This included a question on the number of hours per week they provided care. Three-quarters were unable to give a response, many stating 'all the time' in lieu of giving a figure. In interview they also explained that caregiving was often intermittent or sporadic, and reactive to need. This suggests that many young carers not only do not keep track of how much caregiving they do, but that for a large proportion it can be a variable and unpredictable amount.

There are many reasons, then, to question the accuracy of the Census figures. They may

have overestimated young people's caregiving – eg because any child who gave an hour of support would 'qualify' regardless of what this consisted of and who received it – or have underestimated it – eg because adults will often have answered on behalf of their children and may not recognise, or even know about, all the caregiving that they do (or may have reason to want to conceal it).

And, when the revised definition of young carers is taken into account, they also fail to include any clarity on the types of caregiving being provided or the impact of a caregiving role for a young person – elements now considered fundamental in assessing whether a young person should be counted as a young carer.

Whatever the effects of these flaws have been in skewing the figures in different ways, in combination they serve to undermine confidence that they are an adequate estimation of the scale of young people's caregiving.

Findings from the Census dataset that have been published offer further evidence which might lead one to question the accuracy of the figures. For example, although there were increases in the proportions of young carers in every region – which one

would expect – a large variation from region to region was reported (eg over 40% more young carers in the South East as compared to less than a 2% increase in the North East – ONS, 2011). This seems odd. It is difficult to account for such extreme variation.

Findings for adult unpaid carers were very different – with little proportionate change and both increases and decreases.<sup>42</sup> Whilst there may be many reasons for this, one conclusion could be that the question worked well for this type of caregiving, but was less effective for young people's caregiving.

<sup>41</sup> Almost all the research studies which have estimated scale have looked at the number of hours of spent caring as one factor in deciding whether a young person is a young carer. In the Census more than four in every five of the 5 to 17 year olds identified in the findings were in the lowest range, and may have been clustered at the lower end of this range... but we will never know what proportion were only caring for an hour or two a week.

<sup>42</sup> The data for adult unpaid carers has been published, giving more detail around geographic area rather than only by region.

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### 3.4 Discussion – and ideas for better measurement

This leaves an unsatisfactory situation. There is only a poor sense of the true scale of an issue which research has amply demonstrated can have a negative effect on the lives of many young people, and unresolved issues around definition and terminology which may continue to thwart better understanding in the future.

Only the most basic aspect of defining a 'young carer' – their age (a young carer must be aged 17 or less, with the lowest age most often having been set at five years old)<sup>43</sup> – has remained consistent in the terminology, but other criteria have been subject to alteration, revision or extension over time, including:

- whether or not those receiving care need to be resident within the same household as those providing it
- how far the scope for caregiving extends – more latterly explicitly incorporating those who require support due to addiction or substance misuse
- how relevant the impact on the carer is to attribution of status/assessment/ measurement of caregiving.<sup>44</sup>

In order to make for authoritative measurement, it would help if these issues could be finally resolved, but, leaving this aside, the question remains: is it possible to accurately measure the number of young carers in the population?

It is not appropriate to lay out here a detailed prescription for a methodology, but the following 'principles', in combination, should serve to underpin a thorough exercise to measure the number of young people who could be classified as 'young carers' using the most recent definition:

*The term young carer should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances... A young carer becomes vulnerable when the level of caregiving and*

*responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances.*<sup>45</sup>

In proposing these principles, the assumption is made that the more technical aspects of conducting a robust study would be taken care of for any exercise which took place (eg an appropriate sampling strategy, thorough consideration of research ethics etc). It has also been assumed that the bedrock of any research to estimate the number of young carers will be a survey – though, as discussed later, there may need to be other exercises to complement this for some groups.

<sup>43</sup> Although, as discussed earlier in the report, this has been muddled to some extent by the research published around 'young adult carers' which blurs the boundaries in relation to age and has used different bandings (from 14 to 25 inclusive, but sometimes different ranges within this).

<sup>44</sup> Another aspect of young caring that has not been adequately resolved is the degree to which caring for siblings – in lieu of a parent who is incapacitated – 'counts'. In the UK this is alluded to – and much of the research describes it, indeed sibling care as one component of caring has often been measured, but not directly named in any definition. Many of the effects of caring for a healthy sibling would parallel those associated with caring for an incapacitated parent (eg less free time, constraints on time for school work, physical ill health if missing sleep etc), and one could reasonably ask why would a young person who looks after a baby sister for an hour or two every day while his mentally-ill lone parent mother sleeps count as a 'young carer', whilst the same situation would not pertain if he did this because she had to work in the evenings (ie the imperative was solely economic).

<sup>45</sup> However, this wording still precludes caring for people outside the family, and so, to fully research the scale of young caring as it is most broadly-defined, would require the insertion of a phrase which adds this wider group.

## **Principles for developing a methodology for future research to better measure the number of young carers in the population**

### **1. Ask young people themselves about their experiences (whenever feasible).**

This first principle is fundamental to the whole approach – not keeping to it would likely undermine the accuracy of any findings for a topic like this.

Perhaps the most positive development in the changing terminology around young people's caregiving has been the introduction and extension of the personalised approach to assessing young people's caregiving (despite the significant additional challenges this poses for researchers) – and the only way to find out about how caregiving affects young people is to address questions directly to them.

(Clearly there will be some exceptions to this – but for most children aged 8+, self-completion of a basic questionnaire should be possible.)

### **2. Use the most young person-friendly option – such as an electronic/online questionnaire – to facilitate participation.**

Answering the questions needs to be as easy as possible. Clicking a mouse (or touching a screen), having the ability to route respondents away from questions they do not need to answer, and perhaps even including a soundtrack, are all ways in which the experience of taking part can be improved for young respondents – and should improve the quality and amount of data collected.

### **3. Embed an exercise to estimate caregiving within a wider study of issues which interest and will engage young people.**

'Of all the consequences of caring, the hardest one to reveal and examine is concerned with concealment of caring itself.'

**Frank, 1999**

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A number of research studies have served to underline the 'hidden' nature of young people's caregiving and the barriers to revealing their status that young people experience.<sup>46</sup> This is not a surprise. The Children's Society has conducted research on disadvantaged young people for many years and a common theme is the reticence they feel to discuss sensitive issues, particularly those related to their family.

Given the nature of this study there would be a need to counter this (through appropriate provision for confidentiality, data protection etc) but also to undertake an exercise that gently elicits relevant information from respondent groups where most will not be answering a particular sub-set of questions on caregiving responsibilities.

To do this it would be necessary to design a questionnaire – and a wider study – that cover issues beyond caregiving but which may relate to it, and which will be engaging for all the young people who take part. (And to have a not too onerous or time-consuming set of questions on caregiving).

The research needs to create an opportunity for young people to focus on different aspects of their lives, family relationships etc, which can, as one bi-product, generate an estimate of the scale of young people's caregiving (but which could also, if well-designed, find out other useful and interesting facts about young people's lives).

#### **4. Ensure that the screening questions asked and measures employed for asking about caregiving are fit for purpose.**

There is likely to be a need to develop new screening questions and new measures around caregiving to ensure this exercise does not fall down in the ways earlier ones have done.

Previous attempts to do this have not proved to be designed well enough, eg the question used in the LSYPE study (replicated in another study: 'Understanding Society') which was too inclusive, or the first question in the Census.<sup>47</sup>

In relation to a sub-set of questions around caregiving tasks and volume/frequency, although instruments have been developed to measure this, these have been framed and phrased primarily for a context where a young person already has the 'status' of young carer

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<sup>46</sup> See the work of Aldridge and Becker (1993 / 1997), Walker (1996) and Frank (1999).

<sup>47</sup> eg The LSYPE questionnaire where the key question was too inclusively-worded, as explained earlier in the section. (The same question was used in another government-sponsored study: Understanding Society).

and is aware of this – and so they are unlikely to work well within the context of a survey to all young people.<sup>48</sup>

Rigorous piloting and cognitive testing with a broad range of young people – ie not exclusively with those already 'aware' of caregiving roles – would be necessary to ensure that the screening and measurement items work well for all respondents.

## **5. Employ young person-friendly and well-proven measures to explore the impact of caregiving.**

At the core of the current definition of 'young carer' is a personalised level of assessment of impact which determines whether or not caregiving is problematic for the particular individual concerned.

*'...when the level of caregiving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances.'*

It could logically be argued then, that this introduces the idea of three facets of 'young people's caregiving':

- an 'objective' element (types of caregiving, volume/frequency – related to age, capacity etc – though absolute levels for this have never been defined)
- a 'subjective' element (how much caregiving affects other parts of a child's life, relative to individual context, personality etc)
- an 'outcome focused' element (longer-term impacts – into adulthood).

In relation to estimating the number of young carers, this provides a significant challenge to methodology. Since the proposed method here is a survey (and even if another exercise were undertaken it would likely be similar in terms of logging a 'snapshot' of the situation at a point in time) data for the third element based on outcomes could only be collected through proxy measures (eg how often a young person missed school etc).

<sup>48</sup> It is also important to bear in mind that asking about the amount of care provided by a young person may not generate accurate responses. As is discussed later in the report, young people interviewed for this study were asked about the number of hours of caring they did each week (in a brief questionnaire) but almost three-quarters said they were unable to estimate this because of the eclectic range of tasks being done intermittently and, for many, the 'constancy' of responsibility.

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For the first (as advocated in section four above) there is need for fresh measures to be created which can facilitate a young person to record enough information on whom they care for, why, how much and how often.

But for the second – the 'subjective' assessment – there should be the opportunity for each young respondent to appraise her/his life in a number of ways. There are a range of validated measures of subjective well-being already in existence which would be suitable for this element of the research. These have been used successfully for a series of population-level studies since 2008 (eg The Children's Society, 2010) and have been augmented by the development of additional complementary measures with particular input from children and young people themselves.

To explore how much different levels of caregiving impact on different young people, it would be helpful and appropriate to deploy a set of these measures within a self-completion survey to look at levels of life satisfaction, freedom and choice, self-esteem, resilience, happiness with school, family, peer relationships etc. At the same time, because the same questions would be asked of a nationally-representative sample, they could:

- provide an engaging format for the wider survey (see Principle 3 above)
- add to knowledge around the general levels of well-being among children and young people
- contribute to generating a range of normative values for well-being (to use as a comparator for the levels of young people with caregiving responsibilities and to formulate levels below which 'problematic caregiving' could be identified – eg at what level of objective caregiving responsibility does most 12 year olds' life satisfaction fall significantly?).

Should these principles be followed, they would provide an authoritative and rich dataset from which it would be possible to do two invaluable things:

- 1.** Create an authoritative estimate of the numbers of young carers based on 'objective' measures in order to say how many young people of what age (gender, ethnicity, etc) are doing what types of caregiving, for whom and how much.
- 2.** Say with clarity what the impact of this is on different individuals in different contexts – and develop detailed estimates of the numbers of young people who experience negative impacts or positive outcomes of caregiving, facilitating improved understanding of what might contribute to problematic levels of caregiving, whilst at the same time preserving a sense of the potential benefits to young people of having a caregiving role.

With additional development work and cross-referencing with other datasets on children's well-being, it may also be feasible to develop an assessment framework which can be applied in practice to understand how caregiving is impacting on young people over time.

## Summary

**In this chapter the accuracy of estimates of the number of young carers has been questioned in the light of different methodologies employed in different studies, and the flaws in the approach used in the two Censuses – highlighting how a changing definition has hampered attempts to measure 'young people's caregiving'. A number of principles which could underpin a survey approach to more adequately resolve the estimation challenge, and offer other benefits around considering the impact on young people's health and subjective well-being of a caregiving role, have been proposed.**

## 4. Responding to young carers: identifying, working with and appropriately meeting need

This chapter of the report has five sections which explore different issues in relation to how young people with a significant caregiving role could be more readily identified, engaged with by professionals and worked with appropriately to support their role in caregiving for others and to better meet their own needs.

To do this, the accounts of 45 young people have been analysed in detail. They all had a caregiving role, represented different ages, ethnicities and (as is described later) had very different home situations.

The sections explain how the young people talked about their caregiving roles, how they felt that caregiving impacted on different areas of their lives, what they thought about 'needs', and how they related to the status of 'young carer'. The final section outlines their reflections on how services and individual professionals could best respond to young carers and their families. The views of some of their parents are also included.

The original prescribed aim for the study was to 'explore the needs of particular groups'. The

concluding section to this part of the study (pp 88-93) reflects on this in the light of the issues described in the chapter, but in the main text few distinctions (aside from in relation to age) are made between young people from different groups.

### 4.1 Being a young carer

The young people who participated in this research all came from projects which worked with young carers<sup>49</sup>, but aside from knowing this – that, at some point they had been referred to and engaged with a carers project, and were currently involved – no other information was sought in advance of meeting them.<sup>50</sup>

In order to understand and contextualise their caregiving role it was necessary to know more about each young person's circumstances and family situation, and about how they themselves viewed and made sense of the caregiving that they did. In individual interviews, and to a lesser degree in groups, they were encouraged to talk about their experience of caregiving and how this fitted into the rest of their life.

This section of the report gives more information on the young people who took part – their individual and family characteristics – and outlines the variety of caregiving roles they were performing.

### Characteristics of the young people who took part

#### Gender

Of the 45 participants, 28 identified as female, 16 as male and one preferred not to say their gender.

#### Age

The strategy used to recruit young people to the research ensured that there was a spread of ages in the sample – partly because the aims for the study necessitated data collection in relation to specific age bands. Interviews were conducted with young people aged from nine to 23:

- 10 participants were aged 9 to 10 years
- 22 participants were aged 11 to 17 years
- 13 participants were aged 18 to 23

<sup>49</sup> Ideally the sample would have included young people with a caring role who were not engaged with a support service, but a pragmatic decision was made during the design of the study to adopt this approach because of the complexities of finding unidentified young carers and other constraints determined by the proposal (eg the need to collect data from three subgroups and in four areas of the country).

<sup>50</sup> An attempt to segment the sample and to focus on young people who had only recently joined projects in order to inquire specifically about their experiences around identification, referral etc was thwarted because some of the projects found it difficult to manage this request (see Appendix Two).

### Ethnicity

Similarly, for one element of the research there was a need to speak to young people from BME backgrounds. The sample therefore included roughly an equal split between participants from Black, Asian, Mixed, and White backgrounds (see Table 4, right).

### How caregiving roles varied

#### Who the young people cared for

The young people were asked who they cared for. As detailed in Table 5 on the next page, the majority (32) were caregiving for one person, and most for their mothers. Of the remainder, five were caregiving for one sibling, two for their father, and one for their grandparent. The remaining five were caregiving for multiple people: three for a parent and a sibling, one for both parents and one for two siblings. In total, nine (a quarter) participants were caregiving for a disabled or unwell sibling.

Alongside this, 11 participants indicated that they also had to look after a sibling or more than one sibling in lieu of a parent. This issue is discussed further in the next section on types of caregiving.

**TABLE 4: Ethnicities of young people in the sample**

<b>Black</b>	<b>11</b>
<b>Asian</b>	<b>10</b>
<b>Mixed</b>	<b>9</b>
<b>Other/Prefer not to say</b>	<b>2</b>
<b>White British</b>	<b>13</b>

#### Types of condition

The types of conditions that family members had and that young people supported with varied considerably, as did how they were described by participants. Information about the health conditions of those cared for by each participant was gathered from 39 participants via a self-completion survey at the outset of an interview. This was complemented by discussions during interviews. Physical health conditions were most often cited by participants as the reason they provided care (28 young people reported these; 72% of the sample). Some referred to specific conditions, such as Parkinson's disease or epilepsy. Others described the symptoms that were experienced, for example 'a rare progressive neurological illness – can't walk or talk or eat solid food or do anything unaided'.

A third of young people were supporting someone who had a mental health condition. This smaller number may also reflect the difficulties that may be experienced in explaining or quantifying care around things like making someone happier as opposed to specific physical types of support.

Smaller numbers were supporting family members due to learning disabilities (six young people reported this for the person they gave care to; 15% of the sample) or sensory impairments (five; 13% of the sample). A number of the young people who were interviewed were caregiving for people with multiple disabilities or health conditions, or were looking after more than one person.

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

**TABLE 5: Who participants provided care for**

Who they cared for	Number
<b>One Person</b>	
<b>Mother</b>	<b>32</b>
<b>Father</b>	<b>2</b>
<b>Sibling</b>	<b>5</b>
<b>Grandparent</b>	<b>1</b>
<b>Multiple people</b>	
<b>Parent and a sibling</b>	<b>3</b>
<b>Both parents</b>	<b>1</b>
<b>Multiple siblings</b>	<b>1</b>

**Household composition**

Particular types of household were over represented in the sample (see Table 5, above)<sup>51</sup>. The majority – around two-thirds – of the young people lived in lone parent households headed by their mother, and a similar proportion lived with siblings (see Table 6 on page 42). Three of the young people were caregiving for someone whom they did not currently live with – one was a carer for a parent they did not live with and the other two had moved out of their family home

but continued to provide care to a parent. Both of these siblings were planning on moving back home after their studies. There was another participant who had recently returned home having graduated.

**Time span for young people's role as a young carer**

The young people were also asked about how long they had been a carer for. For many – as illustrated in Jolene's story (see right, p41) – this was a difficult question to answer. They felt that their role

had not had a 'starting point' – it was something that they had always done:

'I can't really remember really. It's hard to tell. Mine gradually increased, so it's always been there.'

**Mary, 23**

Eighteen participants (40%) said they had been caregiving since they were aged six or younger. Some gave specific ages, whilst others said they were 'way too young to remember' or that they have been caregiving for 'as long as I can remember'.

'For me it started when I was a toddler, but obviously you don't understand, you're helping around and stuff like that. I got signed up for young carers when I was 8 or 10 so for me that's when it started but I think I started when I was younger.'

**Katie, 18**

<sup>51</sup> This reflects the findings from other studies which have suggested that young carers are more likely to be caring for a female parent (eg Dearden and Becker, 2004).

## Jolene's story



Jolene is 19 years old. She lives alone with her mum who has suffered with mental ill health since Jolene was young.

Jolene's earliest memory of helping to look after her mum was when she was in infant school. She would bring her mum a bowl of cereal for her breakfast, help her to take her medication, and comfort her when she cried.

Her recollection was that she did these things because she realised they needed doing and there was no one else around to help.

When Jolene was still at her first school her mum had to spend some time in hospital – and Jolene was given extra support at school and cared for at home. Her mum's condition improved and she came back home, and as she gradually recovered better health the support to Jolene became less and less.

Soon there was no extra help or support for Jolene or her mum and, not long after, Jolene moved to secondary school where no one knew about her situation at home.

Jolene began to feel stressed and anxious and her mum suggested she saw a counsellor. The counsellor identified that Jolene was a young carer and referred her to her local young carers service – though Jolene says that she didn't really understand about this and no one told her what was happening. She went to the project for a few months, but felt it wasn't really for her and decided not to keep going.

Jolene did not tell anyone about the support she gave to her mum at home. When she was 16, her school held an assembly about young carers, but Jolene didn't feel that enough was explained about how it can affect your life – and her classmates

were laughing, joking or looking confused – so Jolene sat there keeping quiet and feeling embarrassed about what was going on at home.

Things were better at college. The environment was more informal and relaxed and there was a tutor who Jolene got on with really well and whom she felt she could trust. She told him about her mum and the situation at home and he listened and offered helpful suggestions on how to manage her studies. She liked the fact that he was approachable but didn't ask her about the challenges she was having with providing care for her mum – it was enough that he knew and would make allowances when she struggled to do assignments on time or had to take days off.

Now Jolene is at university. She hasn't told anyone there about her caregiving role. She knows that she should, and she's been given information about where to go if you need to get help, but she's waiting until she knows which tutors she really likes and trusts – or until there's a problem – before talking to someone.

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

**TABLE 6: Who the young people lived with**

<b>Household composition</b>	
<b>Parent/guardian in the household</b>	
<b>One parent/guardian at home</b> <small>(Female adult – 26 households; male adult – 5 households)</small>	<b>32</b>
<b>Two parents/guardians at home</b> <small>(In each case these were female-male couples)</small>	<b>14</b>
<b>Siblings in the household</b>	
<b>Lived with sibling(s)</b>	<b>32</b>
<b>Did not live with siblings/had no sibling(s)</b>	<b>13</b>
<b>Was the cared for person resident in the same household?</b>	
<b>Yes</b>	<b>42</b>
<b>No</b>	<b>3</b>

### Aspects of a caregiving role

Descriptions of what young carers do have focused on a range of aspects of their role: what type of care they provide, how much and how often, whether this is shared with others, and so on. In this section some of what the young people said about their caregiving roles is presented, as are some of the thoughts interviewees had about their role more generally.

#### Types of care

Previous research studies have proposed different typologies of the caregiving done by young carers (see Box One page 44). Most of the young people who took part in this research spoke readily about tasks that fell into practical, domestic support and physical types of care. These were easily identifiable and quantifiable:

'I help my mum by putting the dirty clothes in bin bags and taking them to the washing.'

**Bobby, 9**

'I just help my mum a lot – like I used to be cooking because my dad was trying to find work, so when he was trying to find work I would come home from school and make things.'

**Billie, 18**

'My mum has arthritis; movement is very hard for her so I try to help out with anything: carrying, moving stuff – predominantly that.'

**Darren, 15**

Some young people also spoke about more intimate types of personal care like helping with feeding, bathing, dressing and toileting needs:

'Sometimes I help my nan get changed coz she can't bend down as she has arthritis in her back.'

**Armin, 9**

Others described a variety of tasks related to household management included attending appointments, interpreting, managing or helping with completing paperwork, and managing finances.

'I literally do everything on my own - sorting out bills, paperwork – I have always done them.'

**Samayya, 16**

However, after further reflection many interviewees highlighted further elements of their role which point to the wider and less quantifiable elements of caregiving. Some spoke about how they had to be reactive to need:

'You're just doing things to fit around who you're caring for.'

**Fiona, 10**

'If there's anything she needs to be done, then I am normally there to do it.'

**Alex, 15**

Some recounted different kinds of 'emotional support' – sometimes simply being there or 'being alert', keeping someone company, or calming them down:

'She doesn't like being alone as much anymore because she used to love being alone and having her own space but now, when she's going, she's like "could you come with me". It's weird for her to ask me because she's never asked me that.'

**Serena, 16**

'I have to put him in the right frame of mind if there's an appointment, get up hours in advance, make sure he's up, and make sure he actually gets there.'

**Seema, 18**

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**BOX ONE: Typologies of care from other research studies**

Frank (1999)	Frank (2003)	Joseph, Becker and Becker (2008)
<p>Cooking</p> <p>Housework</p> <p>Shopping</p> <p>Physical care</p> <p>Personal care</p> <p>Parenting younger siblings</p> <p>Out and about</p> <p>Responsibility for parents</p>	<p>Practical tasks – cooking, housework and shopping</p> <p>Physical care – lifting or helping someone use the stairs</p> <p>Personal care – dressing, washing, helping with toileting needs</p> <p>Looking after younger siblings</p> <p>Managing the family budget, collecting benefits and prescriptions</p> <p>Medication management</p> <p>Helping someone communicate</p> <p>Emotional support – listening, calming, being present</p>	<p>Domestic support</p> <p>Household management</p> <p>Personal care</p> <p>Sibling care</p> <p>Practical and financial support</p> <p>Emotional care</p>

This 'person management' aspect was sometimes extended to remembering things for the person they cared for, because their condition made them forgetful or absent-minded:

'Sometimes she can be, sort of...I'm trying to think how to describe it... information doesn't get into her head, so I have to explain things over and over.'

**Jolene, 19**

In some senses then, although attempts to categorise a young carer's role can offer an understanding of particular tangible components, it cannot give an insight into the more nebulous and pervasive parts – or the all-consuming feeling of responsibility that caregiving involves for some young people.

'Basically everything really, just running someone's life for them.'

**Mary, 23**

### Amount of care provided

As well as taking part in an interview or focus group, the young people were also asked to complete a short questionnaire. One of the questions was about how much time they spent caregiving each week.

Their responses showed that they found this a difficult calculation to make. Across the 41 completed questionnaires, the majority (30) had not been able to give a figure for the hours they spent caregiving, and some indicated that it was 'all the time' (10). Of those that did record a time, these estimates varied so widely – from as little as half an hour to over a hundred hours – that it raises questions of how accurately the time spent caregiving can be recorded.

In interviews and focus groups, some young people also commented that caregiving was constant – more caring about someone than a particularly time-consuming or practical role (eg ringing home from school or getting up in the night to check that the person they look after is okay) – and that it could be unpredictable with regard to the intensity of practical work involved, as explained by one young woman:

'Because of the illness of my mum → she has got a mental health condition – you can go up and down. So my caring role has always been up and down. I get very quiet places where actually I wouldn't be classed as a carer, and then other moments where I am taking on an awful lot of care, so it's always up and down.'

**Selina, 21**

Or another, whose mother suffered intermittent bouts of severe pain:

'She'll say, "I think my pain's coming back" and then she'll start rolling on the floor and there's nothing that will make it go away.'

**Serena, 16**

An additional factor that young people described related to the volume of caregiving was how this could be changeable over long periods of time, for example reducing if a person who had been severely physically ill experienced improvements in their condition:

'I am doing less things as she's getting better. But sometimes she might be iller on some days than other days so I have to help out again.'

**Eliza, 12**

Or because the young person's skills had improved, meaning they could better manage their own time spent caregiving:

'I think because my mum's getting older, (her condition) can be worse. But as I am getting older too, I am more responsible, I know what I am doing. When I was 10 I didn't know a lot. It's got easier over time.'

**Darren, 15**

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Or increasing as a result of declining health of the person they cared for, or because the young person themselves had taken on more tasks or responsibilities as they had grown older:

'It's been a while, probably since about six or seven, it started off slowly but it got a bit more as I grew up.'

**Chrissie, 18**

### **Level of responsibility**

A number of studies have proposed ways of classifying the varied role that a young carer may have within their family relative to the level or type of responsibility they take on (eg Frank, 1995). Interviews and focus group discussions for this study demonstrated that household composition was closely linked to the level of responsibility that a young person had. There seemed to be **four types of carer** amongst the young people who participated in this research<sup>52</sup>.

### **1. Solo carers**

'I am just a lone carer'

**Bobby, 9**

Some of the young people were living in a household with a lone parent, so caregiving responsibilities fell solely to them. This close, dyadic relationship could have benefits, which young solo carers recognised:

'I can talk to my mum about anything. We've talked about colleges and problems through high school and stuff like that. If I ever need to talk to someone I talk to me mum, and she always gives the best advice and we make decisions.'

**Katie, 18**

But there could also be additional pressures because of the intensity of the relationship. One participant, highlighted how spending lots of time together could be difficult:

'I argue a lot with my dad. Coz he gets really..you'd think that spending a lot of time with somebody...but it's not really spending time though, it's just stuff that you have to do it's not like it's quality time though... the rest of the family we don't speak to.'

**Seema, 18**

<sup>52</sup> These definitions are based on the perspectives of those we interviewed – other family members may have had different perspectives. Also, these categories are likely to change over time, and as such these are very much based on a snapshot at the time of the research.

## 2. Main carers

Similarly to the 'solo carers', some young people who lived in households with other members as well as the person who needed care described their role as being 'in charge' of things<sup>53</sup>.

For example, some explained they were caring for a parent as well as for younger siblings, or took on caregiving responsibilities whilst another parent worked, or where other siblings or other family members were not primarily responsible for care for other reasons.

'I have my dad. My parents are divorced, but he's looking after her today so that I can come here.'

**Mary, 23 (no siblings)**

It might be assumed that the 'main' carer amongst a group of siblings would be the oldest, but in this sample not all sibling groups fitted with this model. Instead often other factors, such as personality, capability, motivation and gender also determined which sibling had taken on the majority of caregiving responsibilities.

'I have a little sister at home, she is 16 but I have kind of protected her from picking up caregiving roles because I don't think she should have to, so she does occasionally come and give me a hand, but it's at a level where it's just chores for her because I won't let her do any more.'

**Selina, 21 (oldest sibling)**

'[Serena's older sister] will call Serena to come and help me rather than her doing the helping. It's not something that comes natural for [the older sister], you know she would like to help, it's just not something that she feels able to do.'

**Serena's mum (Serena is the youngest sibling)**

## 3. Team carers

'We've got each other. And my brother.'

**Dipti, 14**

Some young people explained that caregiving was, for them, a 'team effort' involving another adult or sibling (or more than one), which allowed for flexibility around the main practical tasks:

'Sometimes I help my mum to take her pills, remind her "oh you need to take it" and get her water. If I need to take her to the bathroom then I will take her. Clean the house, the dishes, sometimes. We all divide it. So we do different things every day.'

**Matika, 14 (youngest sibling)**

'They more or less do the same things. I would say that Moreley really enjoys cooking so he does do more on the cooking side. But they

<sup>53</sup> For a small number of these young people this was true even when they did not live in the same household as the person receiving care (ie for older young people who had left home).

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more or less, whoever is available, to be honest. Both of them will do things – I will ask them to do it and both of them will be available to do that.'

**Jones family mother**

Within families there were sometimes conflicting views on how equally things were shared – for example, one situation where one of the older siblings considered that there were equal contributions made:

'Everything is shared and equal. It is good because when you are younger, you know how to do things and when you are older you are quite used to it.'

**Ruth, 21**

Whilst her sister maintained that this was not the case:

'Most of the time it's me, but it's whoever mum calls basically. Before we had a rota, but that got scrapped

so now it's just whoever mum calls will just do it.'

**Sally, 18 (middle child, but oldest living at home currently)**

This was also echoed by their mother:

'She [Sally] took on a caregiving very early. I remember her being tiny and pushing me in a wheelchair and wanting to push me, so she was five or six when she started to do caregiving in that sense. [The younger ones], gradually did, but because the older ones would take more of the responsibility they didn't care for me as much. It was mainly between [the older ones].'

**Smiths family mother**

For team carers, changes to care need, life stage, age or other circumstances had tended to alter the distribution of responsibility for caregiving roles over time.

#### 4. Supportive carers

Finally, there were those young people who acknowledged that their role was mostly 'supportive' - ie that there was another main carer within the household. For the young people who expressed this, their role often remained a significant one from their perspective:

'I help my dad get stuff for her [disabled sister]; I get her pram, get clothes for her, and sometimes help to do nappies and that.'

**Sonya, 10**

Or their role could have particular impacts regardless of the seemingly lower level of responsibility:

'I have had my nose broken twice...my brother is very strong. He doesn't know what he's doing so sometimes he can just swing and slap you, when he's getting excited or bored or something.'

**Fiona, 10**

## Support from others outside the immediate household

Young people were also asked about whether they received support from others outside their family which assisted with their caregiving role and, if so, who this was from and how it worked.

### Professional support

Interviewees spoke about a wide range of professionals who had been involved in supporting their family – whether at the time of their interview or in the past – including social workers, family support workers, carer support services, mental health workers, cleaners, personal assistants, home carers, health visitors, GPs and other health professionals, and pharmacists. In addition, some talked about the professionals that they had received individual support from, including counsellors and mental health workers, as well as supportive tutors, teachers and pastoral care staff.

However, nearly half of the young people (49%) told us that – from their perspectives – there was no direct support for the day-to-day practical elements of care in the home, including for solo and main carers:

'Nobody...no one. We would have to get there [to appointments] on the bus in the snow and the rain or whatever it was. We had to do everything on our own.'

**Samayya, 16**

For some of the young people, young carers services were the only formal support that they were in touch with:

'[My project worker] – yeah that's basically it. And my friends.'

**Matika, 14**

'I don't have a social worker, but I get enough support... from my family and from young carers [project].'

**Armin, 9**

'Support' in relation to professionals was a concept that was differently understood and interpreted by the young people. Some explained that individual, supportive professionals came and went over time; others said that professional support was not provided directly to them, but was experienced indirectly (eg by doctors or care assistants who visited their homes).

### Informal support

Some young people described aspects of informal support or whole networks. This might involve extended family or friends and neighbours:

'I think – because we've got a big family – they are pretty much the workers.'

**Eliza, 12**

'When I am at college, my next door neighbour goes in and also my best friend, she lives up the road and she will go and check on my mum and that gives me a sense of reassurance.'

**Abi, 18**

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For some young people, however, there were additional strains in involving other family members in caregiving.

And some young carers and their immediate families were isolated with no informal support because of their geographical location, relationship breakdown, or for other reasons:

'It's just me. My friends or my cousins, they are in quite different places, so it kind of takes time for them to come. So I have to help my mum with stuff.'

**Bobby, 9**

#### Identity as a 'young carer'

Although not strictly a characteristic or a 'characterisable' element of the young people who participated in the research, it was important to know the degree to which they understood, related to and adopted for themselves the terminology most often used (by adults) around 'young people's caregiving'.

Interviewees were asked to reflect on and discuss their experiences, and to say how they saw and would describe their 'role'. Where appropriate they were asked whether they accepted or used

the label of 'young carer' when talking about themselves.

Given the constraints around recruiting a sample for the study – that participants had been formally identified as being carers and were in contact with a young carers service – it was not surprising that most were familiar with the term and its meaning.

Some were very connected to a 'young carer' identity and derived a sense of status from adopting the label:

'I am that kind of person that I just say anything – I don't feel like sad about like – if I say "I'm a young carer" my friends'll ask me what that is, but I wouldn't feel shy.'

**Eliza, 12**

However others told us how they did not use the term, or that they did not feel an affinity for it and would not closely identify with it.

'I just don't use it really.'

**Aardesh, 14**

'I don't see myself as her carer, just her helper sometimes.'

**Jolene, 19**

One participant described how:

'It's just something that you do, isn't it? Like an "everyday" thing – you don't meet someone and they say, "yeah, I wear foundation too".'

**Seema, 18**

Another interviewee felt uncomfortable giving a title to something that was just a part of family life:

'It's not a title, it's just a way of living. I don't know – you don't really get praise for calling yourself a carer. Using the word, I am not against it, but it's just I don't feel it needs to be glorified that I am a carer.'

**Noah, 23**

Some of the young people shared alternative ways that they thought of their role, including phrases like 'looking after', or described themselves in other ways, such as 'guardian'<sup>54</sup>.

<sup>54</sup> The resistance of some young people to being described as a 'carer' was also highlighted by a project worker. She indicated that young people did not connect with the terminology used by adults around young caring and gave a number of reasons for this: caring had been a part of their lives for as long as they could remember, it was an entrenched part of their life or daily routine, it seemed peculiar to talk about it as something 'separate' as opposed to being integral to their existence.

## Discussion

The most important theme which resonated across young people's descriptions of their caregiving role was the wide variety of experiences they had. No two stories were the same once a full consideration was given to all the elements for any individual young person, and this underlines how challenging it is to capture what it means to be a 'young carer' and the resultant problems faced by researchers in adequately categorising young people's caregiving. This also points to the barriers professionals encounter when identifying, assessing or responding to the needs of young carers.

There were also other issues which arose in analysis of the responses that interviewees gave and the accounts they provided:

### The potential importance of gender in caregiving situations

Many of the young people were caregiving for their mothers, a phenomenon which is echoed in other research studies (eg Dearden and Becker 2004 found that the majority, 70%, of young people were caregiving for mothers, particularly in lone parent households).

Also, the majority of the young people who were interviewed for this study were female. It is not possible to know how much this

represents the overall profile of young people's caregiving (the gender of caregivers, or those cared for) but suggests that issues related to gender may be important in assessing individual situations, and in researching the phenomenon.

This research highlighted a number of factors that may contribute to this:

- The Census suggested that young women may be more likely to take on caring roles as they aged; for the 5-9 age group, 0.6% of boys were reported as carers, compared to 0.7% of girls, however by 20-24, 4.4% of boys were reported as carers, compared to 5.4% of girls (2011 Census – table CT0415).
- Lone parent families – which are overrepresented among households with young carers – are predominantly headed by women.<sup>55</sup>

Whilst some participants reported that some things are more expected of girls than boys., this study did not explore in detail the views of the young people who took part about what they were expected to do in relation to gender roles, nor did it ask parents a great deal about their expectations and how these related to gender. These are issues that would benefit from further study in order to better understand how they affect young

carers themselves, their wider family and the professionals with whom they interact.

### Varying impacts according to household context

It was striking how much household context made a difference to the impact on a young person of their caregiving role. Principally, for those who were solo or main carers the complete reliance on them affected many other parts of their life and led to particular uncertainty and potential disruption:

'You can't predict it. You know the morning you wake up – that's the furthest you can plan ahead. Things change all the time. It's like today, I had today all mapped out and mum was not a part of today. But my mum rings me this morning and she was really ill. What am I supposed to do? You have to drop everything.'

Mary, 23

<sup>55</sup> Over 90 per cent of single parents are women and 10 per cent are men (ONS, 2015) Families and households, 2015. Table 1. (source: Gingerbread website)

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'You have to pre-plan everything, and arrange for people so she isn't left on her own. Like today I had to say I am going to the carers support centre so someone else can come in, or if my nephew can come down so mum's not on her own.'

**Abi, 19**

### **Absence of informal support**

Among the young people interviewed for this study there were many who had no informal support networks – perhaps because of parental relationship breakdown, exclusion of the extended family from involvement or knowledge of the situation within the immediate family, situations where extended family members lived in other cities or countries, or for other reasons.

This reflects the findings of other studies which have challenged the assumption – often made in relation to minority ethnic families – that some groups will be self-sufficient with regard to care because of the strength of community links, but that caregiving itself can happen in isolation (eg Welsh Assembly, 2003; Mills, 2003; Hubert, 2006).

### **Self-identification as a 'young carer'**

The responses of interviewees to questions about how they viewed their caregiving role and responsibilities suggested that there may be difficulties with using the (adult-devised) terminology of 'young people's caregiving'. Even some young people in this group, who were engaged with specialist young carer services, indicated clearly that they were either uncomfortable or did not identify with the language within the contemporary discourse around young people's caregiving, though most understood it. This suggests that those outside the 'system' may well be excluded, with the labels currently in use unwittingly acting as a barrier to their accessing of services.

## **Summary**

Trying to capture and categorise what it is to be a 'young carer' can serve to undermine an understanding of the complexities in this role. Every situation is individual – because of the range of types of care provided, the different levels of caregiving done according to household composition, the variations in disability, illness or condition that exist and the degree to which some young people may or may not feel a fundamental responsibility for their home and family. The reactions and coping strategies of individual young people themselves will vary. Differing amounts of formal or informal support can mitigate the impact on a young person, but may also cause additional stresses and strains. And every situation is dynamic, subject to ongoing flux and change – whether that be over months and years, or, in some circumstances, on a day-by-day basis.

It is also important to remember that for this study, the situations of young carers in households where there were likely to be higher levels of unpredictability and irregular change – eg those where a parent or carer has an addiction to alcohol or illegal drugs – were not the focus. Children and young people in these circumstances may often experience even more onerous and uncertain change in their caregiving and self-care role.

## 4.2 Being a young person and a young carer: How caregiving impacts on young people

In the previous section information was presented which highlighted the wide variety of caregiving responsibilities and the complexity of roles which the young people in this research described.

However, to regard young people primarily through the lens of their caregiving role would give a limited perspective on their lives as they grow up and on the range of their needs as they mature.

The young people interviewed for the research also spoke about wider aspects of their lives – their passions, problems and plans – and how important these were to their identity:

'I think you get that though, if there's a restriction in your life like being a carer, then you feel the need to promote yourself in other areas, throw yourself into other things – you kind of find that one thing that separates you from your caring role.'

**Ashley, 21**

They also explained how caregiving impacted on them, sometimes leading to different choices or constraints. But, as is described below, those who reviewed and reflected on this emphasised how caregiving was just one part – though an important part – of who they were, with its own challenges and benefits.

### **The benefits of being a young carer**

Many of the young people in the study wanted to stress the benefits they had derived from being a young carer. Some of the younger interviewees pointed out the positive aspects of having a caregiving role:

'I think it's fun – I get to know my mum more, bond with her more.'

**Eliza, 12**

'It's nice to be the one to support them and stuff. Even though you can't really do anything about the situation...it makes me feel needed and wanted in the house. Before I had never felt like that.'

**Alex, 15**

And some older young people presented a stoical view, and described how caregiving had strengthened family relationships over time, how it had boosted self-esteem and confidence, improved skills and aided them to mature in ways they were proud of:

'It makes me feel good. The fact my mum can – if she has a problem, that she can confide in me.'

**Jolene, 19**

'My caring role, it's important to me. It helped me to mature. Maturity. It helped with my empathy too – being empathetic and understanding how people feel. At its worst it was difficult and scary. Right now I feel rounded because of it.'

**Noah, 23**

It was clear how much young carers valued their role and, over time, had developed coping mechanisms and resilience to deal with the difficulties that could arise.

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## Responsibilities and worries

It was apparent from many of the young people's accounts that the health and well-being of the person they cared for could be a major, regular and ongoing source of concern. Most of them talked about their worries in relation to this.

For younger participants this could be a generalised and all-consuming worry:

'When I worry about my nan, I can't focus.'

**Armin, 9**

'I do lots of stuff to help my family, because I am trying to help my sister, because I am worried about her.'

**Kirsty, 9**

'[When] I go back to school – mum's got to go into hospital. I am pretty scared about that...I am actually not quite sure what I am going to do while I am at school because I know I am going to be worrying constantly.'

**Iris, 14**

And for older young people, other more tangible concerns featured heavily, often in relation to financial strains on the family:

'I think that the biggest source of stress at the moment is the money.'

**Ashley, 21**

'Because even though it doesn't hit a young person directly, it doesn't mean it doesn't affect their lives. DLA<sup>56</sup> doesn't affect me, but it affects my life anyway. All this bedroom tax doesn't affect me because I don't own a home, but still affects me.'

**Seema, 18**

Other concerns included pressures the young people themselves were facing, such as how they would cope if the balance between their caregiving roles and other elements of their lives were disrupted:

'The workload is really intense [at university], but I have been keeping up with it. But if something with my mum happens, I am worried that I will have to take a lot of time off.'

**Jolene, 19**

<sup>56</sup> Disability Living Allowance

### **Impacts on moods, behaviours or health**

Interviewees spoke about a range of ways they felt the stress of caregiving had manifested itself. Some described effects on their mood – especially irritability and anger, sometimes directed at those closest to them:

'I feel really unappreciated because I do so much stuff but because my dad's not well he doesn't even see it anyway...but instead of getting upset I just get angry and walk out.'

**Seema, 18**

'I get stressed once in a while because of my school work as well, it's quite tough. I have to manage all of that, and home, and I do really get stressed and I end up shouting at these guys [her younger siblings] sometimes. Before it used to be fine but now if I am in a really bad mood, I just have to let it out on them.'

**Samayya, 16**

Some interviewees explained how the combined strains of caregiving and other pressures had led to difficulties around controlling their behaviour or to problems with mental health:

'I didn't know how to control my anger...I managed to get angry enough that I got grounded, I got a detention from school, because of what I did.'

**Baruk, 11**

Some young people noted how caregiving had affected their physical health:

'[I remember] pushing my mum in a wheelchair up hills – it was a hard one because the chair wasn't light.'

**Sally, 18**

'I have been ill quite a few times and have been in pain where she leans on me when I help her down the stairs, and I get back pain or stuff like that or my body aches.'

**Samayya, 16**

## Alex's story



Alex is 15 years old. She is in her final year at school. She enjoys school and has ambitions to go to a specialist college and then move abroad to further her career. She plans to work in photography and fashion.

Alex lives with her mum and two younger brothers. She helps her mum by supporting her with taking medication, doing household chores and going shopping. She also helps to look after her younger brothers, including dropping them off at school (before going to school herself) and cooking for them. She worries about one of her brothers because he is not very happy at school.

Although Alex likes school, and wants to study hard and do well,

there have been times when she has fallen behind. Things got a bit tough at school, and she became angry and then depressed:

'There was an incident in school where I lost the plot. I put all my rage into the teacher. I made her cry. I felt so bad. I was very stressed at the time and I think I needed someone to shout at. I put all my anger into her...I was so depressed I cried the whole day.'

Alex has a mentor at school. This support has been helpful, but has not always been enough, as she explained when describing what happened in the wake of her outburst at the teacher:

'From there on everything got worse. My grades fell. That's when my mentor had to tell the teachers that I was not in a good state.'

Even throughout these difficulties Alex protected her mum from knowing that she was having problems at school:

'My mum didn't know... 'coz at home I was always laughing and stuff.'

But eventually her mum had to be informed as a referral was made to a local mental health service. However, since then she hasn't heard anything and she is concerned about the lack of any response:

'I think they have forgotten about me!'

## Impacts of material deprivation

Research has shown that disabled adults have a higher cost of living, are more likely to be unemployed and, as a result, are more prone to living in poverty than their peers<sup>57</sup>. There is also evidence of the link between caregiving and poverty in the research literature on young carers – for example indications that young carers more often live in households where no adults are in work, or where family income is below average (Dearden and Becker, 2004; The Children's Society, 2013) – and in wider research around deprivation in families (eg Ridge, 2009) which has identified that children in low-income families often take on caregiving responsibilities and other household tasks.

As noted previously, many interviewees in this research said they worried about family finances, and the realities of living in a poor household were highlighted by many. Some described shortages of basic necessities:

'The last few months mum has been short on money. She was struggling with things like rent and everything, groceries. So I had to lend her money, coz I normally don't like spending my money, but I gave her money for the last week. It's been a bit up and down but we are coping.'

**Alex, 15**

Others described how limited resources jeopardised their physical health or participation and achievement at school:

'When I first moved in with my dad I had to stay on the sofa – and it wasn't a very good sofa, and I had to stay on it for about a year and I got really bad back problems.'

**Seema, 18**

'I don't have a laptop so she has been trying to help me get some money together from the council to get a laptop so I can do my school work. I get a lot of detentions and stuff because I haven't done my homework.'

**Iris, 14**

<sup>57</sup> See for example [http://npi.org.uk/files/7814/0490/1005/Disability\\_long\\_term\\_conditions\\_and\\_poverty.pdf](http://npi.org.uk/files/7814/0490/1005/Disability_long_term_conditions_and_poverty.pdf)

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One older young person reflected on how this might affect his choices around accommodation:

'It's another reason that I am considering going back so that instead of paying a landlord I can pay my mum some rent so she can eat basically.'

**Noah, 23**

And even the youngest were not immune to the impacts of financial hardship:

'Bailiffs, I hate them.'

**Bobby, 9**

Some of the parents who were interviewed also said that their family's activities were hampered by having a limited income:

'When you're not working, you can't afford to really take them and do what you would like to do with them.'

**The Smiths' mother**

For some families the impacts of illness or disability were compounded by issues related to inadequate or unsuitable housing. Some young people were living in homes where the accommodation did not meet their needs, or those of the person they cared for. For example, some physically disabled adults or children were having to navigate stairs at home (often with the support of a young carer), and a number of interviewees had to share a bedroom with a sibling who had individual needs:

'I sleep with her in her room so if she needs anything in the middle of the night, I am there to take her down or get her something because in the night she kind of wakes up. It's like she is kind of sleeping but she kind of shouts and screams and cries in her sleep.'

**Samayya, 16**

'[It would be better if] I had my own bedroom. Just before holidays she gets really excited (and) stays up late, keeps me awake; one night she just read the Aristocats book over and over and over 'til she read herself asleep.'

**Pippa, 9**

### **Restrictions to social life or interests**

Not surprisingly – and as other research has often shown before (eg Frank et al, 1995) – the young people interviewed described how caregiving responsibilities were a constraint on their social lives or interests outside home.

Some of the younger interviewees were acutely aware of this:

'I did a lot of stuff with my mum, helping her, so I didn't really go out the house much.'

**Oscar, 11**

'I don't get to see my friends very often.'

**Arun, 11**

And older interviewees understood some of the benefits of socialising that they were missing out on:

'I don't really have a lot of free time! I like to socialise when I can. I am so absorbed with everything at home that it's nice to talk to other people...it de-stresses me. If I am

worrying about stuff it goes away when I am talking to people.'

**Jolene, 19**

'I am, really focussed on, like, seeing my friends at the moment – otherwise I don't have any social life, that is the only thing that is keeping me sane!'

**Tilly, 21**

Some interviewees talked about the many activities outside school that they were engaged in, but a number said that their social lives were strongly shaped by their caregiving role and responsibilities. Hobbies and interests were often home-based – including music, art or computing – or activities were done nearby:

'I go to the park a lot – there's a park right outside my house.'

**Violet, 12**

### **Impacts on school, college or university**

For almost all the interviewees – aside from a minority of older young people who had left education (three of the sample) – school, college or university were a major preoccupation of their lives.

Many of the young people who were interviewed spoke positively about school:

'I enjoy school... learning in general.'

**Aardesh, 14**

'My teacher says I am one of the smartest in my class.'

**Armin, 9**

Some appreciated the respite it afforded from the situation at home:

'I like school because I can kind of get away from all the stress at home and laugh everything off with my friends.'

**Alex, 15**

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'I am happy for the break of going to school.'

**Ali, 13**

However, it was also clear for some that the demands of education, or the need to mix with peers at school or college, could be difficult because of the responsibilities of caregiving or the negative comments that other children made.

#### **Missing school**

Some young people said that they had missed school, either for substantial periods, or intermittently over a long timescale. This may have been because of the disability or illness of the person they cared for:

'My mum's disabled, and so most of last year and this year she's been in hospital so I didn't get that much attendance.'

**Bobby, 9**

'Sometimes mum's condition would be so bad that I would have to stay home with her for a while, make sure she eats and she takes her medication and everything, and then go and I would be quite late for school.'

**Samayya, 16**

Or because their own health (including mental health) had suffered:

'I think when I couldn't get up and missed school – one time I missed nearly a week of school – I hated it so much and no one understood.'

**Serena, 16**

Some interviewees described how this had affected their attainments or enjoyment at school, for example how their participation in extra-curricular activities could be hindered:

'I had a few like drama shows and things like that, but that was eight weeks of the year. If you're not there all the time – which I wouldn't be – it's, "You can just stand in the corner and be a tree" or something, so I wasn't really involved.'

#### **Struggling – or not – to do homework or revision**

Many of the young people shared accounts around how keeping up with school or college work could be difficult:

'With my revision for my exams, I really struggled because I couldn't juggle it. I couldn't juggle looking after my sisters and revising as well and they were always wanting something to do and...I'd have to revise and keep them entertained.'

**Billie, 18**

'It's a difficult time in that sense...I wouldn't say frustrating but sometimes it can be hard. Now I am going into GCSE the workload is massive. It's hard to fit in that and caring for my mum, but I do it.'

**Moreley, 14**

And some parents reinforced how hard it could be for them to support their children with their school work:

'I remember having to go to school and apologising to them for not being able to really be involved in the children's homework, because I couldn't read for very long without it hurting me and then to sit up and even to have them read to me, I found very draining so I had to apologise for that.'

**Smith family mother**

'I can't always get involved in [their homework] because I might not always feel up to it because the painkillers have quite serious side effects and stuff so, it just depends how I am as to how much help I can offer them.'

**The Jones' mother**

However, it is also important to stress that some of the young people who were interviewed were clear that they could manage fine with homework (contrary to what they felt might have been expected):

'I always do my homework.'

**Dipti, 14**

'I manage my school work, I have also moved up a year so when I was going into Year 9 I was put into Year 10, so I done my GCSEs a year early and have just done my AS-levels as well.'

**Samayya, 16**

### **Being bullied**

Being bullied is a relatively common experience among young people<sup>58</sup>, and a number of the interviewees relayed that this had happened to them. For some this was specifically in relation to their caregiving role (or at least because their bullies knew they had a disabled relative and had targeted them as a result):

'I only moved school because I was getting bullied because I had a disabled brother. They would call him names like he wasn't a normal person. And they would take the mickey out of me even more because I would say that just because he's disabled, don't mean he's not a normal person.'

**Fiona, 10**

<sup>58</sup> See The Children's Society's series of Good Childhood reports on children's well-being.

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'When I got told I was a young carer, my brother started coming to school to see me (and) I had to play with him more often. After his school he would, and my friends wouldn't understand and they started bullying me.'

**Baruk, 11**

'I had to leave the assembly hall, I got sent home because I was crying. The person sat next to me was shouting really horrible things. Because there was a video of people doing things [caregiving for relatives], and I was in that video and I let them show it, and then people were shouting horrible things and I got sent home.'

**Iris, 14**

**Getting into trouble at school**

Some of the young people described sanctions they had had from their teachers which they attributed to their caregiving role or to the effects it had on them:

'I was brought out of a lot of classes and kind of put in a room on my own to go through the work.'

**Ashley, 21**

'I think one of my teachers – my form tutor – she gave me a detention for no reason. I felt it was built up from other incidents when I would come in late or had been a bit emotional or stressed.'

**Noah, 23**

**Long-term impacts on education**

The older young people who were interviewed and who had elected to stay on in post-16 education (these made up the majority of young people in this age group in the sample) explained how balancing caregiving at home and school life had the potential to impact on long-term progress and reduce options. One participant described how deterioration in her mother's condition had meant she had not been able to prepare for the next steps in her education (although support for this had subsequently been forthcoming):

'When my mum got more ill, I didn't have time to apply for any colleges so for the whole summer she [learning mentor] helped me apply for college.'

**Billie, 18**

And another said that her lower-than-expected results (due in part to her mum's worsening health) had limited her choice of university:

'I didn't straight away, I didn't get into my first or second - so I changed my course and then got into my second choice.'

**Tilly, 21**

### **Future plans**

Planning for the future – or thinking about it – was something that different interviewees spoke about in different ways. Some had high aspirations relating to education, travel or careers and felt relatively unconstrained by their current caregiving responsibilities:

'If there's a better city for a specific university, I will go there. Because I have a dream – so if I have to travel away, so be it.'

**Darren, 15**

'(I'll) go into medicine, because of the things that I have done, I feel quite passionate about it and it's something that I really enjoy doing as well. I couldn't think of a better thing to choose than go into the health sector and do something like that.'

**Samayya, 16**

Others were more pragmatic about maintaining their role at home:

'I will stay in the house until I am about 25. Just to make sure my brother is out of trouble.'

**Baruk, 11**

'Well I was considering moving out, and I spoke to my mum about that and she was encouraging me to go actually. But especially with everything that's been happening recently I just wouldn't feel comfortable going somewhere else. Just in case.'

**Jolene, 19**

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And some were ambivalent at the time they were interviewed:

'I honestly don't know what I am going to do [about whether to move out to study or stay at home and study in a local university]. That's why I was going to go

to [a university close to home] but I've got so stressed out I just want to get out. I know that sounds bad but I do.'

**Seema, 18**

Also, one interviewee was compelled to be cautious about her plans because of the poor prospects for her mother's health:

'(I'd like to be) travelling the world – but that's not going to happen...I don't know what I will be doing, arranging her funeral, crying.'

**Mary, 23**

## Selina's story



She's been looking after her family for a long time and works hard to ensure that her younger brother does not have to do too much around the house so that he can focus on his studies.

Selina says that she would like to go to university and travel the world. At the moment though, the needs of her family come first.

She has found ways to make life better. Talking with other young people in similar situations, and finding a job (with support from her project worker) with an employer who recognises the skills she has developed because of being a young carer and who is flexible enough to facilitate her meeting her commitments at home. She is also looking at Open University courses to allow her to continue her studies at the same time as looking after her family.

Selina's story highlights how difficult it can be for young people to plan for the future if they have caregiving responsibilities – and also shows how adaptable young people can be.

Selina is 20 years old and has a younger brother who is 16.

She is the main carer for both her parents – her mum suffers from a physical disability and her dad has mental health problems – so caregiving is a huge part of her life.

## Discussion

This brief overview surveys the many issues that young people discussed in terms of the rest of their lives outside their caregiving role and the impacts that caregiving had on them. In many senses this serves to underline the fundamental point (made at the end of the previous section) that difference was more important than commonality of experience – that the effects of caregiving varied according to family circumstances, household resources (more of the sample came from materially-deprived backgrounds than from affluent ones), personality, a young person's own health and so on.

What also came through is that the stereotype of a young carer who is unhappy, struggling

or failing in education and pessimistic about the future – a 'victim' of their situation – was not supported by what many young people said in this study.

The young people in this sample were encountering difficult problems – not just the disability or ill health of a loved one, but also poverty and often less choice and opportunity than many of their peers – but many were positive about their lives and looking forward to the future despite this, and some (especially older) participants were vocal about the benefits of being a young carer.

The positive benefits of being a young carer are perhaps less appreciated and certainly less measured in research on the phenomenon, although some

studies have emphasised this aspect (eg Becker, 2000; Frank, 2002; Burack-Weiss, 2006), when appropriate support is in place. Using self-report measures of well-being, alongside objective measures of elements of caregiving (type of task, frequency etc) to estimate the scale of young people's caregiving – as proposed in the principles put forward earlier (see p33) – would allow for a better understanding of the range of beneficial impacts of caregiving for young people, and an analysis of the characteristics, circumstances and levels of caregiving which link to different levels of well-being (eg life satisfaction, resilience etc) would make for a more nuanced debate about the pros and cons of being a young carer.

## Summary

Being a carer can have a variety of impacts on a young person's life but these are interrelated and, to a large degree, interdependent on many other factors. Often other things are the cause of their difficulties and many of the young people who were interviewed were keen to stress that it was not their caregiving role that was the cause of their difficulties, but the other issues which affected them over time.

Young carers will likely worry about the person they care for – especially if, for example, they have a condition that is deteriorating – but their concerns will be amplified when there is not enough money in the household budget to pay bills or buy food. They may have mood swings and become angry, or suffer problems with their own physical or mental health, or there may be constraints on their capacity to keep up with the demands of education – but some will thrive and achieve highly. And some will regard the future with apprehension, pragmatism or fear, whilst others will have high aspirations and feel unconstrained by their domestic circumstances.

At the same time, the positive aspects of caregiving should not be forgotten. Both 'older' and 'younger' young carers spoke about things to do with caregiving and responsibility within the family that they liked, and the older subgroup in particular reflected that they had acquired personal benefits and learnt invaluable skills which they were proud of.

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### 4.3 What does help? Young carers' experiences and views on useful support

As part of the interviews and group discussions, young people were asked about their experiences of professional support from young carers projects and services, from teachers and educational institutions, from social care and medical agencies and others.

They reported a mixed set of views on what had happened – some negative and some positive – but most were aware of the value of good support:

'A year ago I was extremely depressed. I probably thought that it would just get more difficult as time goes by and there would be no solution. But now it's more like I'm more at ease. I know there are people who have my back and can help me with my family situation. A year ago I didn't think there would be any help.'

**Alex, 15**

In the interviews they were encouraged to reflect on these experiences and to explain what had been most helpful and why. Their answers to this are presented in this section alongside the ideas they volunteered for useful and effective support in terms of the direct delivery of service and in terms of associated issues, such as raising wider awareness of some young people's caregiving roles, improving identification and improving the accessibility of services.

#### **Experiences of support from universal services**

##### **Services and support for the person whom the young carer was looking after**

The young people who were interviewed made a distinction in their accounts between support provided to them and that given to the person they cared for.

The importance of the latter was clear, in relation to improving the life of the person who was being cared for, but also to alleviate some of the pressure on the young person her or himself. This could relate to large issues like the availability of appropriate psychiatric support or small things like the installation of an emergency call system for a disabled parent:

'That's the lifeline we have at home, because if I'm at university, at least my mind's at peace, because if anything happens to my dad, he can contact [emergency response service] and they can come out to him and help him whatever situation he's in.'

**Ashley, 21**

As part of this, an issue which resonated across the young people's accounts was the degree to which positive experiences of support to parents (or others whom they cared for) were linked to the efforts made by professionals to also include them appropriately in information-sharing or decision-making:

'We used to have a social worker. He used to ask me questions, and give us activities to do while he talked to us.'

**Felicity, 9**

'My doctor is really good. He acknowledges that I am a young carer, which is great, because he talks to mum about stuff, but he will talk to me as well, and ask, "Is that okay?" It's nice that he's not just talking to me – which excludes my mum – but is talking to us both.'

**Abi, 19**

### **Support from schools and colleges**

Not surprisingly, young people spoke a lot about their experiences in relation to education. Amongst many accounts it was apparent how much the pastoral support and understanding offered by some staff in schools and colleges was appreciated by young people:

'When work's been late or I haven't been concentrating so much in class they have been understanding.'

**Ashley, 21**

'For me, I had specific teachers in school – I call them my "mentors". If there was a time that I felt down or stressed, I would go to them and speak to them about how I am feeling, which helped quite a lot.'

**Sally, 18**

One young person talked about the particular benefits of one-to-one support in school:

'When I was younger, the more I held it in, the more angry I was. And every time I told someone I felt like I was being judged. My learning mentor...she wouldn't judge me. And we'd make jokes about situations that made me angry...so counselling – having someone to talk to helps the most.'

**Billie, 18**

Another recalled how her school had shown flexibility to ensure her post-16 pathway was the best it could be for her:

### **Experiences of support from specialist young carers projects**

All the young people were involved with specialist projects and some had been taking part in group activities, benefitting from individual work etc from their young carers project for a number of years<sup>59</sup>.

Interviewees recounted many positive experiences of their time with young carers projects:

'Young carers give us a break from stuff when it's hard. Groups and that, and trips to help us socialise more than we're normally used to.'

**Joe, 11**

<sup>59</sup> nb The different projects and services operated different models of practice. Each of them was asked to explain how they worked with young people in a questionnaire. An outline of their responses is given in Appendix One.

'There's nobody is there – no one who can actually help?'

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They spoke about the benefits of time with their peers. This provided them with the 'opportunity' to relax and have a break from commitments at home:

'With young carers (groups/services) you've got support and help and advice if you need it. But you've also got that time away from your caring role where you can just be a young child or a teenager and you can hang around with people your own age, but also people in the same shoes as you.'

**Katie, 18**

For some, this related to activities and opportunities they otherwise would not have had:

'You do things that you wouldn't be able to do because you're caring for your mum... you can walk around and see stuff more. We went to (a football stadium) – I wouldn't

have done that otherwise.'

**Moreley, 14**

'Since coming to this service I have got to do things that I wouldn't have been able to do...making a film, meeting the people I have met – things like that.'

**Ashley, 21**

Whilst for others, the importance of relationships with friends in a similar situation was paramount – a feeling of connection and trust:

'You felt, after a time, you feel connected to them. They play with you. You make pizzas with them, they put flour on you and you joke around. It's easy to talk to them when you have the one-to-one sessions and stuff.'

**Billie, 18**

'The difference between young carers and a normal environment is that there's already that common thing that links you. One barrier's already broken.'

**Noah, 23**

'I am really happy to go there because when I am down and stuff my friends are always there to help me and make me happy.'

**Kirsty, 9**

And some interviewees spoke about the benefits of an affirmation that they were not alone in having a young carer role:

'All of my friends (here) know but they don't make fun of my mum and they understand because most of their mums are sick as well.'

**Armin, 9**

'When nobody knew about me and I started coming to the club I felt alone because none of my friends had somebody who was like disabled or had problems with them. So I thought I was the only person and the odd one out. But then I started coming to young carers and it made me feel better.'

**Fiona, 10**

'It's good to talk to other young carers... it actually made me realise that caregiving for mum is not the end of the world, there are other people that are going through worse situations.'

**Sally, 18**

### **Wider support by project workers**

As well as providing the space for peer relationships and friendships, project workers were also frequently spoken of by interviewees as understanding, supportive and trustworthy. They valued how they allowed young people to steer the conversation, and didn't focus on the caregiving role per se.

'The first interview we had I didn't really talk, because I just find it so weird! But after she's not like – the way she talks to younger people it appears she's really calm, not nagging and stuff like that. It's easy to talk to her.'

**Serena, 16**

And some described the additional support that workers in some projects provided to families. For example, one young person spoke in glowing terms about the way a worker at her project would take an active role with families whom she knew needed additional help:

'[She] really supports everyone, even though it's not really her job to do all the other bits that are going on with families. Like we've been having a lot of problems with housing and stuff, so she's helped with that... She wrote referrals to the council and everything, things I would never do because I wouldn't know that. She's always helped my mum – coz of her stressful condition and everything – she's always helped her cope with it.'

**Samayya, 16**

And another explained how her project worker had collaborated with her school to ensure that her mother was in receipt of appropriate welfare benefits, something that had helped relieve some of the pressure the young person herself had been feeling:

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'The school kind of helped out my mum because I was feeling depressed and not concentrating very much and that was a concern...they've been helping mum with benefits, which has been really helpful for her...I am very grateful they have done something – they could've just left it but mum's at ease right now because of the help of my teachers and [my project worker].'

**Alex, 15**

Through being identified as young carers, the young people in this research had experienced helpful interventions – especially from dedicated young carers projects – which had mitigated some of the demands of their caregiving role.

## Discussion

Many of the young people who were interviewed had positive experiences of support from professionals in a range of services, and especially from young carers projects.

Their stories conveyed the importance to them of involvement in the support that was being given to the person they cared for (eg by being told what treatment was being prescribed by doctors, or what input there might be by other healthcare staff, social workers etc), so that they were informed and could have an appropriate stake in decisions. They shared experiences of individual good practice in relation to this – and also of situations where they had been unacknowledged or excluded, though these have not been reported here. At the core of their accounts was a feeling that professionals should respect their often vital role in looking after someone.

With regard to education professionals, again many of the young people said that staff had been understanding of their home life and had exercised

discretion and flexibility in making allowances for this, which had supported their progress and attainment.

And the young people who were interviewed were particularly appreciative of the support – and the way it was provided – from the specialist projects they were involved with. This had afforded them much-needed respite, affirmation, opportunity and the understanding and acceptance (particularly of their peers) that it was difficult to find elsewhere. In some cases project workers had also intervened with their families in a holistic way, and in collaboration with other professionals. This had been much welcomed by the young people who gave examples, as it had produced tangible outcomes that would otherwise have been difficult to achieve and because the work had been done in ways that were tailored to the needs of the individuals in the families involved.

A young Black man with short dark hair, wearing a blue button-down shirt over a white t-shirt, is leaning forward on the backrest of a black wheelchair. He is looking directly at the camera with a neutral expression. The background is an outdoor urban setting with a building and trees, slightly out of focus.

## Summary

As part of their caregiving role young people will often come into contact with professionals whose primary focus will be on supporting the person that the young person cares for: doctors treating an illness or monitoring a disability, physiotherapists providing physical care, social workers working with the family etc. Many of the interviewees in this study gave positive accounts of good practice by professionals who were in this position, describing how they had adopted an approach that also took into account the needs of the young carer who was involved. Interviewees also explained how educational staff could be particularly helpful where they had been aware of and willing to acknowledge a young person's caregiving role, and were flexible around some aspects of schooling to ensure that a young person could manage their work as well as their home responsibilities.

Young people in the study explained the invaluable support that they had received from specialist projects, support which had offered many things that were not available elsewhere: respite and release from caregiving and responsibilities, opportunities to do things that would otherwise be out of their reach, care, learning and understanding, especially from their peers. And, perhaps most importantly of all, a feeling that they were not alone in their caregiving role.

'There's nobody is there – no one who can actually help?'

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## 4.4 Accessing or receiving support: What makes this difficult?

'It would be weird to ask for someone else's help.'

**Serena, 16**

There are many ways that professional support could have a positive effect on the life of a young person with significant caregiving responsibilities. High quality and responsive support for the person they care for could reduce the physical caregiving burden for a young person, or improve their quality of life (perhaps by offering opportunities for respite and activities outside the home) and appropriate provision could also make the life of the person they were caregiving for better (maybe by expanding their choices around socialising etc). However, difficulties in sourcing and accessing adequate or helpful support, or keeping it once it was in place, were important issues for the young people who took part in the research.

This section of the report focuses on the different factors that had hindered young people and their families' access to professional support or services, and the issues that had impacted on the usefulness of services which young carers and their families had received.

Most often a number of factors had combined to militate against a young person or their family

receiving the support that they needed, including their or their family's own lack of awareness of what was available, motivation to make use of it, or desire to disclose that there were needs within the household. At the same time, other factors were identified that were associated with how services were organised or delivered which reduced accessibility, or issues around how professionals behaved or perceived their role. Preserving a helpful service input had also been challenging for many families.

Young people, parents and professionals who were interviewed talked about all these things, proposing factors they were conscious of which would inhibit them requesting support or had prevented their use, or ongoing use, of services. They related experiences of service provision that had undermined their confidence in professionals being open or sympathetic to their situation – and which had thereby acted as a deterrent to further efforts to seek support – and they spoke about aspects of service delivery that had not been helpful.

This section presents their experiences and views related to 'universal services' (education, health care, social care, etc), and what they said specifically about specialist young carers provision.

## Difficulties in accessing support: factors relating to young people and their families

- Young people (and families) who elected not to disclose they were a 'young carer'

Some interviewees – both young people and parents – explained that although they were aware of a caregiving role which may be excessive, they were resistant to telling others and to seeking support (this group reflect the characteristics of those who are 'hard to engage'<sup>61</sup>). This could be for a broad range of reasons. Many young people felt that others would not understand:

'I don't think most people that I know would understand my situation because all their family are healthy. They wouldn't understand. They might think, "oh that's what you'd normally do as an older sister". But it's not.'

**Alex, 15**

Or they felt that others would make negative, ill-informed judgements:

'People make it worse than it is and treat you differently.'

**Noah, 23**

'There was a huge stigma when I was at school and about depression and mental health and if I then said I am a carer...I would have to say my mum had a mental health condition. That would send a flurry of Year 8 judgements because there was no understanding of carers or mental health. So that's why I didn't tell.'

**Selina, 21**

Other younger interviewees were concerned that revealing their role might leave them open to being bullied<sup>62</sup>, or that if they disclosed their caregiving role it might be taken away, potentially by others who would not do it well, or that strangers would come into their family (something they did not welcome):

'You don't want them to say "stop that caring".'

**Bobby, 9**

'They might copy you and do the wrong things for your family and mess things up.'

**Faruk, 11**

Some young people were concerned that they might be seen as seeking preferential treatment (eg at school):

'How do you explain it without it looking like you just want them to let you off?... You don't want to fight your case for something. It's just a bit embarrassing.'

**Seema, 18**

<sup>61</sup> See Boag-Munroe and Evangelou, 2010 (discussed in Chapter Two)

<sup>62</sup> And this was an experience that some reported when their status had been revealed at school.

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Others admitted that they, or their parents, were too proud to seek or accept help:

'I think it's really difficult for me. Just like my mum I am a very hard-headed person. I hate asking people for things.'

**Alex, 15**

Also, some older young people minimised their need for support, sometimes comparing themselves to others who they said had more onerous responsibilities:

'She dresses her mum, I don't have to dress my dad. There are other people worse off than us.'

**Seema, 18**

The degree of protectiveness some young people or parents felt around disclosing a young person's role was heightened in some cases because of prior experiences and worries that the family might be assessed as being unable to cope and the children taken into care:

'My mum had a real fear of social workers, so the rule in our house was what happens in these walls stays in these four walls...she thought they would take us away.'

**Selina, 21**

And some young people had become disillusioned about the prospects for a useful outcome from revealing their caregiving role:

'Sometimes I feel like there's no point. People don't really care. They just ask for no reason...Like in college I feel like that most of the time – when they ask me about stuff at home, I feel like they don't really care.'

**Billie, 18**

Samayya's story on the following page shows how fearful families can be about the potential consequences of disclosing the level of need within their household.

# Samayya's story



mum being unwell because she thinks they will not appreciate that mental ill health can be as debilitating as poor physical health or disabilities. Samayya says that she does not spend much time with people in her local community because of this, and that she thinks if she told someone the word would soon spread. Then she worries that everyone would know about her family's business and treat them differently, or not know how to react, or blame her mum.

Samayya is working hard at college. She has started working towards A-levels because she wants to study medicine so that one day she can help other people who are unwell.

Samayya is 16 years old. She has helped look after her mum since she was six or seven, providing physical and emotional support. Her family has lived all over the UK, and most of their relatives live in another country. She has two younger siblings whom she also helps to look after. She says she is slowly training them up to help out around the house and with their mum.

Samayya says that she only found out a year ago that she was a carer. A case worker who was helping the family settle in a new neighbourhood realised that this was the situation and talked to Samayya and her mum.

Although at first Samayya was very hesitant, the case worker thought it would be a good idea to refer her to a young carers service. Samayya was concerned that social workers might separate her from her family:

'What if they find out that I am caring for my mum, and my mum doesn't do anything. What are they going to do – take me away?'

Once she had accepted that it may be helpful and acceded to the case worker's proposal, Samayya and her family have found that the service is really useful – and she is now hugely appreciative of their support. The service has given them opportunities to socialise and enjoy themselves, but also more practical support, for example with finding housing and providing essentials for the family when they needed them.

Samayya says that she does not like to tell people about her

- Lack of self-identification: young people not knowing they were a 'young carer'

Many young people stated during their interviews that they had not known what a 'young carer' was before this had been explained to them (usually only at the time they had been referred to a specialist project, or soon afterwards).<sup>63 64</sup> They said that they had not conceived caregiving as being a discrete, identifiable thing because it had been integral to their existence for as long as they could remember:

'My older brother was profoundly deaf with severe learning difficulties from birth, so that was just my life. I didn't realise that taking him to the shops and communicating with the person at the shops, say when I was seven years old, I didn't realise that was a caregiving role.'

**Ashley, 21**

For some participants the normality of caregiving – particularly in relation to practical, domestic tasks undertaken by girls – had been reinforced by views about what was 'normal' or to be expected:

'My mum told me that she had done this from a really early age, she used to wake up at five in the morning and put the washing on, then they used to go to school, then they used to come back, cook, clean, wash up and everything else.'

**Samayya, 16**

'To be honest, because I am the oldest, and I am the only girl, I will still have the responsibilities even as we grow up. They [younger brothers] might help more, but not as much as I do.'

**Alex, 15**

A number of interviewees also said that the popular portrayal of family life and caregiving in the media (which might otherwise have been an accessible reference point) could be confusing, and not conducive to self-identification:

'Even when you watch charity shows on TV and stuff like that "Children in Need" you would always see people with disabilities, and I was like, "my mum's only got depression – it's only anxiety – she's low sometimes and sometimes she's fine". So I didn't think I was a "young carer".'

**Samayya, 16**

Overall then, a lack of self-identification, prior to the acknowledgement or recognition of their caregiving role by someone else, had been a common experience amongst the young people – and this could be a major block to them accessing support.

<sup>63</sup> Young people who reported this would fit in the group described as 'hard to reach' by Boag-Munroe and Evangelou, 2010.

<sup>64</sup> In fact many were reticent about accepting or embracing the label 'young carer' even after they had been involved with a project for some time - as will be discussed later in the report.

### **Difficulties in accessing support: hindering factors related to poor professional practice**

Some of the factors which could prevent young people becoming better supported themselves were due to a lack of awareness, understanding or sensitivity on the part of the professionals who were working directly with them.

One interviewee explained how a teacher had not acted with sympathy or compassion towards her, offering only pragmatic advice:

'[My teacher] sat me down and asked what was wrong and I was telling her and she said I've got to stop thinking about my mum when I'm at school and forget about her, and (only) when I go home, think about her. That really upset me. She kept me behind for about an hour and that really irritated me.'

**Iris, 14**

Another felt that his teacher had panicked and been too hasty in pre-judging what the issues might be:

'They rushed into it a bit too early. When my teacher pulled me out, she kind of rushed into questions, she would say, "what's wrong, is it your mum?" and it wasn't and that would make things worse. I hardly understood myself and I really had my friends on my back, so I really didn't want any more questions. So personally I wouldn't tell a teacher.'

**Baruk, 11**

In other situations an absence of appropriate responsiveness was highlighted in the young people's accounts:

'In Year 11 our English teacher asked us all to write an autobiography... She approached me

afterwards and said, "I didn't know that was your situation"... There wasn't an, "I didn't know that was your situation, there's this and this (I can do)" it was just, "I have read about it, I know that's happening". And it was left at that.'

**Ashley, 21**

'So my friend when I started school she was like, "you need to tell someone, you need counselling or something" [about feeling depressed], so I approached the head of year and she said, "there's nothing I can do, you need to wait until next week" until a certain day or something. She didn't do anything for me. And then I left it. And then I ended up in hospital.'

**Seema, 18**

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

There were also experiences of how support was dependent on who (ie which adult professionals) young people came into contact with. For example in an educational setting, a young person's experience of the supportiveness of teachers could vary from year to year:

'My college knew and were considerate for the first year, but in the second year they were completely and utterly useless. My first tutor really understood what a carer was and what that meant, but in the second year, my tutor just didn't have an understanding.'

**Selina, 21**

And another interviewee talked about how her perception of a particular member of staff at her school who had pastoral responsibilities had prevented her from seeking support:

'There was a teacher who helps the girls with all their problems, but I hated her. She was

horrible. So she was the only lady who was highlighted that you could talk to. I would never talk to her.'

**Serena, 16**

This issue – of how professionals present to young people – was echoed by a young person who had been receiving support from mental health services:

'I think it's the crisis team who referred me to [name of mental health service]. The referral process was really long, and so we sorted it out, and I got an appointment but I didn't really like the guy. I didn't like him at all. He didn't seem like he was listening to listen, he was listening to pry almost. So I didn't turn up for the next appointment. I just didn't even bother.'

**Seema, 18**

Young people also described other settings where professionals working with them had not picked up on clues that they had a caregiving role which was causing them problems. Some interviewees remarked that, even though the situation in their household had been clear, professionals had not volunteered information about the support available:

'The doctors knew because my mum had been in hospital quite a few times. The doctors and the GP – they all knew what was happening – they knew she was a single parent and everything [about her mental ill health] but they still never told us that you could get support or anything.'

**Samayya, 16**

They also mentioned situations where professionals had failed to notice indications that a young person was a carer, even when this was manifest over a period of time:

'In 11 years of turning up to appointments with my dad, not once has someone said, "Are you this person's carer?" It's been down to me to say, "I care for my dad, can you add that to the record?"'

**Ashley, 21**

'I went to the doctors and they prescribed me some tablets – I can't remember what they were...but they didn't really...I was just really stressed as well. Nothing happened. And then I ended up overdosing on them tablets. And still nothing happened...when I overdosed they didn't try to speak to me.'

**Seema, 18**

Young people also described how professionals failed to share information which might have prompted more support. For example, one young person said that within her school there was a failure to pass on information about her circumstances:

'In the first year...they were making sure I was OK. But I went up to Year 2 and it just stopped completely. Once I got a new teacher they didn't follow up or anything.'

**Jolene, 19**

In summary, there was evidence of a lack of awareness amongst staff in educational, social care and health settings. This led to young people either being approached in the wrong way, or left them unidentified and unsupported.

### **Difficulties in accessing support: hindering factors related to operational aspects of services or support**

Young people and their parents said that there could be many factors linked to how services or support were publicised or operated which could act as barriers to take up:

#### ■ Lack of information

There was an underlying sense across the interviews that young people and their parents had been almost entirely reliant on their own resources to find out about what support might be available - ie they were expected to be proactive to source their own support most of the time.

Many interviewees complained that there had been no information made available to them in relation to the support that might be available in their area:

'I think if I didn't look for the support then I wouldn't have got the support. I don't think the information is out there enough.'

**Serena's mother**

Some explained that such information as had been provided was sometimes not in a form that was accessible, often because of language or literacy issues (which could also make completing the necessary paperwork to access a service particularly difficult):

'It's very difficult, because I don't know much English. I can't fill in the forms about benefits or

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different forms. And [Aardesh's mum] can't read or write, and I don't know how to register with the learning disability, where to go.'

**Aardesh's father**

And a young person commented on how this then added to her responsibilities:

'I would prefer to have people come in and help out with my dad's finances and benefits because my dad can't spell or anything. He's not good with paperwork at all. I have to fill it out half the time, and I don't know what to put in half the time, so it would be good if someone could help fill it out with him, so it wasn't as daunting.'

**Seema, 18**

Another young person explained how jargon that was sometimes used in the information that was provided could be alienating or confusing:

'I'm a "newt". I'm not in college at the moment and I'm not working. Or whatever it is? NEET? What's a NEET for heaven's sake? I am not very "neat"!'

**Mary, 23**

The impacts of poor information provision, sharing or use were myriad, and one young person described how a failure to collect information on the part of her university had led to her missing out on financial support she had been entitled to:

'I didn't find out until third year that I was eligible for extra financial support... and by then it was too late. If it had been on the registration documents, then they could have notified people about the bursaries earlier on. That would have been really helpful.'

**Tilly, 21**

■ **Lack of flexibility**

Some interviewees explained that a lack of flexibility in the provision of services and support was not helpful in meeting their needs, leaving them with few options. One young adult carer said the 'all-or-nothing' approach of a service left her unable to use it, and that this further constrained her social life:

'It would be really helpful if there could be someone who could do my mum some food in the evening but if you have that, you have that all the time – but sometimes I am there, so I was cancelling it all of the time. But now it means I have to do it.'

**Mary, 23**

■ Removal of services and support

Some interviewees commented on how the potential to access services or support had been removed, because many which might have proved to be helpful to them were no longer operating, often due to financial cuts:

'We were told a lot of the things that did exist don't exist anymore because funding has been cut...all these doors started closing right as the diagnosis came – so that's the experience that we have had.'

**Pippa's mum**

**Preserving support: how ongoing changes impact on accessing support**

Many interviewees – both young people and their parents – said that maintaining the support of key professionals had often been disrupted because of turnover of staff:

'Two months, three months, and then they leave. Right now we don't know who is the social worker. We [keep] asking them but they don't answer.'

**Aardesh's father**

The frequent introduction of new professionals could be problematic for young people – especially given the reticence many of them felt around sharing and repeating information about their role (as described previously). But it was also difficult for some of the adults who were the focus of support, and this could have a knock-on effect on the young person too:

'My dad's mental health worker went away on sickness for months on end and – bearing in mind my dad's mentally ill anyway – they started sending round different people each time to the house. Now we've been given a different support worker, but now they are refusing to come round on the grounds that it might be unsafe and things.'

**Seema, 18**

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Some also complained that over time 'general' support, especially by care assistants in the home who could undertake practical household tasks, could become intermittent. In most cases this was because of stringent eligibility criteria which failed to allow for the changeability of some conditions (especially related to mental ill health) – and it could have a particularly negative effect in households where the condition of the person cared for fluctuated, necessitating regular assessments and interruptions to support:

'When she was really ill there was a lot of support around her, but as soon as they saw any improvement in her they thought it was okay to let her go, but in reality she's really up and down. So to try and get the support again is really difficult. It's complicated to try and reconnect again.'

**Jolene, 19**

And some described how cuts to funding had meant that support services no longer operated:

'My mum now, no [she doesn't have enough support]. A year ago I would have said yes but it's all kind of come to an end because of timescales, and funding for one of the workers went. She wasn't funded to work for that service anymore. So now she has just got her GP and the triage nurse at our doctor's surgery, but that's only because I begged for that nurse.'

**Selina, 21**

'My dad used to have a support worker that would take him to the hospital, and then the funding's been cut so that person doesn't even have his job anymore...so all them roles, that's just for me [to do now].'

**Seema, 18**

The impacts of this on some young people could be particularly significant, jeopardising their long-term plans:

'Because [an emergency support service] was in place, it gave me more peace of mind to go to uni. If that wasn't there would I have gone to uni? I don't know. Now I am going into my third year and it's been cut, and it's my final year and it's really important and I am like what do I do? Do I carry on with uni – which is what I want to do – but what if something happens? There's nothing in place there.'

**Ashley, 21**

## Hindering factors for accessing or using the support of specialist young carers projects

### ■ Lack of information

Some interviewees said that they had experienced difficulties finding out about the availability of young carers services. As for all forms of support, the common experience was that young people, or more often their parents, had to be proactive to seek information.

'They should announce it more. I didn't even know about it. My mum found it out on the internet. [Young people] should show more about it. More leaflets and stuff.'

**Eliza, 12**

Young people said that services were not publicised well enough:

'There was no awareness, no teaching, no highlighting of the fact that people could be carers. I know that I can't have been the only one caregiving for somebody.'

**Ashley, 21**

'At uni it's hard to get events where it's known. If I'd seen a stand for disability or carers I would've gone to that at the fresher's fair.'

**Noah, 23**

Not surprisingly, many had seen the internet as the likely primary source of information – but had often been disappointed when they followed up on the 'leads' this had generated:

'Even on the internet, if you find groups they are all shut down by now.'

**Pippa's mother**

### ■ Age groups and age restrictions

The specialist young carers projects which were involved in the research had a variety of criteria in relation the age groups they worked with<sup>65</sup>. Older and younger age limits were in place for a number of reasons such as the 'legal definition' of 'young carer', or funding agreements – but many young people could be (or could become) excluded from support because of this.

The plight of young people affected by upper age restrictions was highlighted by many participants in the research. Some described how difficult it was to lose the support of a project once they had become 18:

'It's that support. I understand that you need to leave young carers because you're older, but it's that support. They have that support but we don't.'

**Chrissie, 18**

<sup>65</sup> The table in Appendix One details the variations across the services which took part in the study.

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

A project worker echoed this and explained how her service tried to allay the fears of those reaching 18 and facing a drop in support:

'What we say to all of ours is, "phone us – even if you're over 18 – and we'll try and get through whatever support we can." There is a massive gap in that transitional stage.'

**Project worker**

Another older young person indicated that the multiplicity of responsibilities that he had made him concerned about the impact of losing the support of a young adult carers service (which, in his case, was available to him until he was 25):

'It's difficult at my age...They assume you're an adult and you don't need so much support. And I think that if you come across confident, people automatically assume you must be OK. But it can all get on top of you.'

**Noah, 23**

And one participant said that, although there were services for adult carers at her college, there was nothing specifically for younger age groups:

'[There's support] For carers, but not for young carers'

**Sally, 18**

Over half of the services who were involved in the study had a lower age limit for referrals of between five and eight years old. The need to support younger primary school age carers was raised explicitly by three of the project workers interviewed who said that their services had experienced recent increases in the number of younger primary school age referrals.

Pippa's story on the next page demonstrates the potential problems around having set age criteria for young carers services and some of the complications which services may encounter due to having to accommodate a spread of ages in their work.

- Loss of resources or projects closing

Some of the young people who were interviewed said that their young carer projects were short of funding or were losing funding, and that this affected the regularity of their opportunities to socialise:

'It's bad, it's bad – you see each other once a month and stuff like that. It's a long time, but if you miss one session you've got to wait so much longer for the next session.'

**Katie, 18**

## Pippa's story



Pippa is nine years old and her little sister, Daisy (who has a learning disability) is six. They get on really well and Pippa thinks of herself as a 'playmate' rather than a 'carer'. She found it hard to describe the things she does that might be part of a 'caregiving' role. Instead she talks about the games they play – make-believe, baking cookies, drawing and painting.

At school Pippa has to keep a look out for her sister because she can sometimes get bullied. She wishes the school would let her play with Daisy more often during the day, so that she could look after her.

Their mum feels frustrated because the school can rely on Pippa to support Daisy and help her deal with her bullying – but the teachers do not seem to appreciate how difficult this can

be for Pippa or give her enough praise for this role (which can make her exasperated and upset). And Pippa has experienced bullying herself – linked to having a disabled sister – which the school are not addressing.

Fortunately Pippa and Daisy's mum discovered recently that there was specialist support available locally, and found that Pippa just met the age threshold for becoming involved, which was quite a relief to her because she was getting worried that Pippa was not receiving the help she might need:

'Because young carers is from eight, and Pippa had just turned eight when we first accessed their service – otherwise it

would have been the year previous and we would have had to wait on a waiting list.'

Pippa really enjoys going to activities organised by the specialist project, and her parents are pleased because it gives her a chance to have time when she can be the focus of attention and she does not have to think about anyone else.

Her mum added that sometimes there are challenges for Pippa in engaging with the group at the young carers service:

'They are 8 to 16, and a lot of them are teenagers – so she is among one or two of the younger ones, but the rest are a lot older.'

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

'There was a limit to the funding they had, so there was a limit to what we could do. They would've loved to have taken us to more places...but their finances were spread a bit thin.'

**Noah, 23**

One participant spoke in particular about the loss of the project's minibus and how this had impacted on her being able to take part in activities:

'Sometimes when we meet up they will top up our (travel card), but sometimes we have to make our own way there. Depending on how much they have will determine if they can pay for our transport. They used to have a minibus and they would pick up everyone, but now we have to make our own way there...buses aren't cheap!'

**Sally, 18**

Project workers who were interviewed also described the constraints on funding that services were having to deal with and how this impacted on the delivery of services. For example, projects explained how they were oversubscribed or had waiting lists, introduced traffic light systems to prioritise referrals, or had to adapt service provision to ensure it remained viable:

'We've had a major cut to our funding which affected the way we ran our groups – which went from two times a month to one time a month, with shorter time spaces as well. The majority of the funding we have to find ourselves, because we're not funded for respite care. We're funded for targeted work...so all the respite services we need to fund ourselves.'

**Project worker**

## Discussion

The young people and parents who were interviewed for the research articulated a wide range of factors which they saw, or had experienced, as hindering their access to or use of services and support.

In some instances issues around access were related to a lack of knowledge – that a young person was a 'young carer' or that their responsibilities were excessive, for example – or to a strong reticence on the part of a family to admit that they needed support. These particular findings resonate strongly with other research around the most disadvantaged young people and how difficult it can be for service provision to 'reach' them (see, for example, Manning, 2014).

In other cases, families had sought support and struggled to find it, or professionals in

universal services had not been sensitive to indicators (eg a young person's failure to complete homework tasks) or responsive to clear evidence of a need for help.

Where families or young people had received support it had often been less useful than they might have hoped – with regular changes to what was being provided and by whom, causing severe disruption to routines and stress to vulnerable adults, as well as to the young people looking after them.

There was also evidence of reduction in wider service provision for families and specifically for young carers themselves, primarily as the result of cuts in funding.

The overall picture, then, was of services and support being far from what they might be or should be to adequately meet the varying needs of young carer families.

These findings resonate with those discussed earlier in the report – that families may be 'hard to reach', but that services and organisations themselves may inadvertently put in place a range of barriers to access, especially for the most vulnerable or marginalised groups in society (Boag-Munroe and Evangelou, 2010; Cortis, 2011; Flanagan, 2010; Landy and Menna, 2006).

It is also important to remember that the young people in this study were already in touch with specialist support – so in that sense they may not represent the experiences of the majority of young carers, who remain unidentified and not responded to. As a result, this study may have failed to identify some factors that are particularly pertinent to extending support to the most disadvantaged young carers.

## Summary

The difficulties that young people experienced in accessing help included their own perceptions and fears, and psycho-social factors that led to assumptions about what was 'normal'.

These issues were compounded by external factors. Professionals and services were often reactive rather than proactive in identifying a need for support. This meant that staff were often not aware of issues, or how to respond to them, or that information was not accessible, inaccurate or difficult to find. Additionally there were problems with how services operated – especially thresholds, catchment areas, and age limits – which, although perhaps necessary because of funding constraints or for administrative purposes, served to exclude some young people from accessing the help and support they needed. That services were often subject to change – including staff turnover, or sometimes loss/reduction of funding and restriction of services or, at worst, closure – was another problem which led to hesitancy on the part of young people and their parents about engagement, as this could lead to an ongoing cycle of the requirement to repeat accounts of sensitive information to strangers and having to build new relationships.

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

## 4.5 How services and professionals can better respond to young carers

There are many clues in the accounts of the young people who were interviewed for the research as to what might improve the support and care they and their families receive.

In this final section of this part of the report, the messages they gave (both overtly and implicitly) around how the shape of services and professionals' working practices could be improved, have been summarised under four headings.

Three of these headings look at broad issues and the fourth is more specifically about the roles of young carers projects – but in many ways they are interlinked.

### **Awareness and sensitivity**

'[If a young person is having difficulties at school] People should pick up on that and ask, "Well, what's going on?" Or if your parents aren't turning up for parents' evening. And doctors. If there's a disabled person and someone's turning up with them all the time to appointments, they should click on and say, "Are you

this person's carer?" instead of putting a leaflet on the side which says "please let us know if you're a carer". Some people don't know that they are. It's down to awareness. Especially professionals. People need to recognise that young people care and that they should be highlighting the fact to that person.'

**Ashley, 21**

Professionals need to be aware of the possibility that a young person may be a young carer. It was clear from many of the young people's stories that the ways in which they had come to be better supported – for this group mostly through engagement with a young carers project – had sometimes been complex and difficult, and often as the result of a crisis:

'Nobody really knew until I started having a little bit of a breakdown and then it kind of all came out.'

**Ashley, 21**

To help avoid this, teachers need to be sensitive to how a young person may demonstrate that they are facing problems. The interviewees in the research spoke about how their moods or behaviours in school (like poor attendance, tiredness or distractedness in class, failure to complete homework on time etc), or other things like the absence of their parents from school events, were indicative of the impacts of caregiving on them or the presence of difficulties in their family. A teacher taking notice and putting these indicators together may have intervened earlier.

And almost all of the young people had regularly encountered other professionals – whether they were working with the person they cared for, or had a role in their own lives – all of whom had a 'duty of care' towards the young person, and many of whom had clear evidence that caregiving was likely to be happening in the household. The young people gave examples of GPs who failed to act on knowledge that an ill or disabled parent may have been severely hampered in their capacity to care for their children, and of social care staff who similarly seemed to have ducked these issues.

Since many young carers are reliant on these frontline professionals to provide a bridge to support (especially those living in the most difficult circumstances where parents

themselves may be resistant, or incapable of seeking support) this suggests that there is a need to continue to improve awareness of young people's caregiving, and to encourage professionals to adopt a sensitive but more inquisitive approach in many situations.

### **'Recognition' and more availability of information**

'Like a lot of people don't even think of themselves as a "carer" but they are still under the same amount of work and stress and stuff as everyone else, but they are just not accessing any of the support. So I think being recognised either by being able to have the tools to help identify as a carer, or like having people actively making sure that people are being recognised, I think that is the biggest thing myself.'

**Tilly, 21**

The previous subsection outlined how more awareness and sensitivity on the part of frontline professionals could improve identification and support to young carers. The interviewees in this research – both young people and parents – suggested that there could be other complementary strategies to increase the likelihood of young people self-identifying as young carers, and understanding the potential benefits of disclosure.

The young people felt strongly that strategies which relied on families themselves coming forward to seek support would be unlikely to work, especially for the most disadvantaged who may lack the skills, resources or motivation to seek help:

'If they are not sure or even aware that [support] it is out there they're not going to go and look for that, they are just going to think that they are alone.'

**Serena's mother**

Approaches targeted directly at young people were felt likely to have the most success. Dedicated sessions in schools (or other places where groups of young people were present) were put forward as one option<sup>66</sup>, employing a young person-friendly format and materials and, ideally, supplemented with the involvement of young people who themselves were young carers and could relate their own experiences:

'If someone knows how I feel, and they've been through that situation, then they will probably understand me and give advice and stuff like that.'

**Matika, 14**

Interviewees said that this 'proactive outreach' and use of 'peer educators' would best be organised, designed and delivered by young carers projects.

<sup>66</sup> Other options which creatively make use of the options to reach out to young people via online media etc could also be used following similar principles.

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

They also stressed that if these types of events were to be successful they would need to be done in the right way ie with a sensitivity that might gently encourage young people to come forward if they needed support, rather than with an underlying assumption that they would be happy to have their role exposed in public:

'They did mention it once. They went round with a leaflet and said, "If you feel that you're a young carer..." and it was it was weird because there would be people around talking whilst you were doing it and you wouldn't really wanna write anything down in front of people.'

**Jolene, 19**

Many interviewees also said that for those young people or parents who were motivated and able to seek information, there was a dearth of useful or up to date material. They commented that there needed to be good information available consistently, presented in the right format and distributed through the right

channels, as a key way of enabling young people and their parents to take advantage of appropriate support.

'I actually did a self-referral and was aware of it because of my own experience of working with young people, not because it [the information] was readily available, because it's not.'

**The Jones' mother.**

### **A stake in care**

'To be honest, even if I wanted to, no one actually listens to what I want. If a social worker comes and talks to my mum, sometimes my mum doesn't even know what I want, I just keep quiet. But it's not always what I want.'

**Baruk, 11**

'Especially with mum, I get blanked out, like we don't exist. Just because we are children, we don't know what's happening. But the fact is that we do know a lot of stuff that is happening.'

**Samayya, 16**

An issue that resonated throughout young people's accounts (regardless of their age, the nature of their caregiving role or the circumstances they were living in) was the vital importance for them of having an appropriate stake in what happened around care and support, whether that be with regard to the person they cared for or for themselves.

Some young people had good experiences of this (as outlined earlier in section 2.3) but more often their accounts indicated disillusionment about professionals' failure to include them, or concerns because no one had taken the time or trouble to explain things in a child-friendly way:

'They don't really speak to me about my mum. They just think I am there to sit there. Sometimes I am hearing things that really scare me. I said to my mum, "why don't they speak to me?"'

**Iris, 14**

Sometimes those who said they had not been adequately involved or consulted also pointed out that the absence of their perspective and knowledge when professionals had assessed the family's situation may have led to poor outcomes:

'I was involved in the child protection conference – I attended that – but the actions that were taken from that meeting, no one asked me whether that would be beneficial...In a kind of big-headed way, I thought I knew best because I knew

her inside and out, it would have been a lot better – for her and me – for that discussion to be had with her and me, even though I was only a teenager.'

**Selina, 21**

'Obviously everything's private and confidential, so if my dad's got an appointment I can't go into the room with him, even if it's just talking to the doctor. So then he comes out – he's got short term memory loss – so he'll go, "He said...err, um...I can't remember." So I don't know what medication you're supposed to be taking, when you're supposed to be taking it, how you're supposed to be

taking it. But they just don't accept that, well it seems to me that they don't accept that young people care for people.'

**Ashley, 21**

For young people the solution to this was straightforward. They wanted their caregiving role to be acknowledged and respected, even if not overtly, by any professionals who were working with the person they cared for. Feeling that they were not well-informed of what was happening, or that people did not consult them or take their views into account, contributed to their feelings of mistrust, exclusion and frustration.

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

### Individual support

Young carers projects provided a number of valued inputs to help young people (see pp.67-69) but many interviewees, including parents, indicated that the individual support provided by some services via a keyworker or caseworker system was particularly important.

The young people themselves, regardless of their age, were clear on the need for this:

'Sometimes I need someone to talk to and tell them how I feel. One day I might feel like, "oh yeah that's cool", but another day I might feel...sometimes I feel different. Sometimes I need someone to talk to.'

**Matika, 14**

'I can't move out of my house, or go off to uni, so it's at that stage that a support worker can discuss how to juggle [responsibilities].'

**Selina, 21**

They talked about the need for this to be a consistent and stable relationship, so that trust could develop, and more prosaically (though importantly for the young people), so that there was not the need to have to repeat and explain their situation and circumstances:

'I don't want to talk to three different people about my situation. I already have two people that know my situation and know what I am going through. It's hard work just going there!...Even now it's very awkward talking to [project worker] or my mentor about it, saying, "oh this happened at home, or that happened" but I am getting used to it.'

**Alex, 15**

'If I get comfortable with people, I don't want to start all over again, because I have done it so many times, I have just had enough. I don't want to explain all over again. She knows everything and it's not as though she talks about it all the time. You don't have to tell her all the time exactly what's happening, she doesn't force you to tell anything. She tells you the options but leaves it up to you how much you want to share. I find that really nice.'

**Sammaya, 16**

And some said that it was helpful if there was an option to maintain contact between face-to-face meetings:

'I only see [project worker] once a week but I know I can call or text her and say I am not feeling well or things aren't good, and she'll be there to have a chat with on the phone or by text, which is nice.'

**Alex, 15**

Some interviewees felt that it was a good idea for the worker to check in with the young person on a regular basis:

'I think for young carers a regular checking in period would be useful, just to see how they are doing – say once every two weeks or something, almost like a support worker. They don't have to come round necessarily, but

phone and say, "how you doing? How you getting on? Is there anything you need in the home?" and just check in.'

**The Jones' mum**

This parent also suggested that it was good if a project worker could act in the role of advocate for the young person if this became necessary:

'But I think that it definitely helps to have some kind of support or advocacy to actually help people that are not able to speak for themselves. In all aspects of life when accessing services it's definitely useful, but there is not as much of that available now!'

**The Jones' mum**

The findings reported in this section suggest a number of key factors contribute to the identification of young carers and to offering them high quality support.

- Frontline professionals – including teachers and healthcare staff – need to be aware of the chance that a young person may be a young carer, and all professionals should more actively exercise their duty of care and be sensitively curious if there are indicators or evidence that a young person may have caregiving responsibilities at home.
- Proactive strategies to help young people self-identify as carers may be useful in enabling them to connect to support services. Specialist projects working directly in schools and deploying peer educators may be an effective way to supplement other strategies and the dearth of accessible and appropriate information available should be addressed.<sup>67</sup>
- Staff in adult services need to be aware of the new duties under the Care Act 2014 to ensure they are equipped to identify young people who may have a caregiving role early in their involvement with a family where an adult has support needs.
- It is vital – in their own interests and those of the person they care for (and to better meet the needs of both parties) – that young people are given an appropriate stake in contributing to care planning or other aspects of the support given to the person they care for or to them, by being kept informed and being consulted.
- Individual support for young carers is fundamental to their well-being. They need a consistent, trustworthy, flexible, responsive, non-judgemental specialist worker who knows them, can advise them or advocate on their behalf, and in whom they can confide or just talk to whenever necessary.

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<sup>67</sup> The Young Carers in Schools programme can provide schools with information and guidance. <http://youngcarersinschools.com/>



## 5. Conclusions

This research has been about the scale of young people's caregiving in England, about the experiences of young people who have a significant caregiving role, and about how to improve support for them, especially for those who may be less likely to engage with services.

Because the study comprised two rather different projects it leads to a number of different conclusions and some broad recommendations.

The more immediate ones – and, in the context of new responsibilities for local authorities instigated by fresh legislation, the more important ones – relate to better identifying and supporting young carers. These are mainly detailed in section 4.3 and section 4.5, but what resonates throughout these accounts is that:

- **Professionals need to be aware of the possibility that any young person can be or can become a carer** so that in their interactions they respond appropriately. This is equally true for staff in 'frontline services' from teachers to GPs or more specialist workers, and is also particularly important for those whose role is primarily to support the person whom the young person cares for. For these professionals, who may not come into contact with their client's family, there is a need to be vigilant to the possibility

that any adult engaged with a service may be a parent.

- **To overcome the likely lack of self-identification – or 'reticence' on the part of young people or their families to present as being 'in need' – a proactive, outreach approach needs to be taken to make known the availability of support and to encourage take-up.** This could take a number of forms (including via peer education initiatives backed by specialist projects as suggested earlier) but needs to be done in a context that is cognisant of the fact that many young carers and their families may want to keep their home circumstances private, or may not be ready to accept an offer of support (ie there need to be opportunities to make contact with support services discreetly at a young person's own discretion).
- **Young people with a caregiving role want to be respected for their contribution.** For some this means 'public recognition' and plaudits, but for others this type of validation is not necessary or would be unwelcome. For all young carers this means a fundamental recognition of what they do so that professionals accept, understand and incorporate this in all interventions with a family and facilitate an

appropriate stake for the young person her/himself as a core facet of their practice.

- **Young people want and need flexible support.** The diversity of circumstances and needs, allied to the dynamic nature of every domestic situation, and the changing context around a family over time – including the developing maturity of the young person her/himself – necessitates responsiveness and agility in support.
- **Young carers want the person they care for to be well-supported by high quality and appropriate services.** If the services and support for the person needing care in the household are not good enough, or their remit does not extend to the types of support which may be required, this will add significantly to the demands on the young person.
- **Families need ongoing, consistent support.** Without stability of key personnel and services – and the ongoing involvement of someone who knows the situation and is trusted by the family – the likelihood of effective support will diminish.

Reading across the young people's accounts it became clear that distinctions could be made around the level of need in families where there was a young carer. High need arose when there was a combination of factors in a

family's situation, including:

- a condition of the cared for person which intermittently undermines or limits their capacity to manage their own life, to manage a household and to look after their children (among our sample this was principally mental ill health – either as the primary condition or as an additional health need; eg the emergence of depression – but it could be addiction to drugs or alcohol, or other circumstances, such as domestic abuse).
- households where the young person was a 'solo carer' or 'main carer' (as described on pages 46 and 47 – for the former where a young person was the only child of a lone parent and took on all the caregiving responsibilities alone, or the latter where other members of the household had subsidiary caregiving responsibilities).
- material deprivation, including poor or inadequate housing.

Any or all of these could be compounded by the other 'status' factors identified in some of the 'more excluded' groups which were part of the original research brief – eg younger children would be more impacted; or young people from some minority ethnic groups may experience more problems around communication with services if English is not the first language for the adults in the household.<sup>68</sup>

But what made situations most acute was when young people and their families experienced change. This could mean situations where this had been difficult to foresee – eg where the cared for person's health deteriorated, where any facet of support is removed or reduced (due, for example, to the separation of parents), or where the young person's own physical or mental health had declined. These crises put additional pressure on the young people in relation to ongoing caregiving, but it was also apparent that even more predictable change could also be problematic (eg geographical moves, school/ education transitions, an older sibling leaving home etc).

For any family where there is already a fragility in the caregiving arrangements – in part because they are reliant on the input of a young person – change is difficult to accommodate and support, therefore, needs to be readily-available, flexible and responsive. And, aside from support to mitigate the effects on a young person of their caregiving responsibilities (eg by offering respite/time out, positive activities etc), it is invaluable if such services can also provide other types of 'family support' – practical inputs, information and guidance (eg in relation to welfare benefits), advocacy, etc and be a bridge to other appropriate services.

Some examples were given by the young people interviewed where specialist workers from young carer projects had taken on this role, at least to some degree, but – if there is a desire to better meet the needs of more disadvantaged and vulnerable young carers – then specialist projects need to have the scope to provide this consistently. Taking a step away from the application of the research findings to improvements in practice, a second set of conclusions can be drawn from the evidence generated for the study.

These relate to issues around terminology and surfaced throughout both projects when trying to interpret what different parties and audiences understand by the label 'young carer', and how this then translates into measurement of the phenomenon or professional responses to need.

For the first project this arose in relation to how different researchers and a government agency (the Office for National Statistics in developing Census questions) had attempted to estimate the numbers of young carers – and it demonstrated that, despite a number of efforts, there remains a lack of clarity and consensus around how to classify 'young carers'.<sup>69</sup>

<sup>68</sup> More detailed research is required to authoritatively establish how these factors combine to reduce service use and accentuate vulnerability.

<sup>69</sup> Although, as was pointed out, the aim of the Census questions was rather broader than this - to estimate the scale of 'unpaid caring' across all age-groups - which was part of the reason why it may not have captured young people's caregiving very well.

In tandem with the critique of research methodologies for estimating this figure, an account of the regularly-changing definition of 'young carer' gave a sense of why those attempting to put a figure to the phenomenon have come up with such different figures. This revealed that, at the heart of the issue, there had been an evolving conceptualisation of 'young carer' and an improving definition which had, more latterly, reached a point where it officially acknowledged the need for individualisation in assessing a young person's status as a carer:

*The term young carer should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances...A young carer becomes vulnerable when the level of care giving and responsibility to the person in need of care becomes excessive or*

*inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances.*

If this is the working definition for estimating numbers it leads to a two-fold challenge for measuring young people's caregiving, ie it asks for a figure for the number of under-18s who provide 'regular' or 'ongoing' care – an 'objective' figure for how many young people do this – but it also demands a more meaningful measurement of 'when the level of care-giving...becomes excessive or inappropriate for that child' – a second 'subjective' and perhaps more important estimate of the numbers of individual young people with a caregiving role who may be 'vulnerable' to negative impacts.<sup>70</sup>

The solution proposed here to generate more accurate estimates which take into account both these requirements is a sophisticated, yet young person friendly, nationally-representative self-report survey on family life, incorporating objective measures of caregiving tasks and responsibilities alongside

subjective well-being measures (with some similarities to a number of data collection exercises which The Children's Society has undertaken over the years<sup>71</sup>).

This would allow for comparisons of well-being between carers and non-carers and would facilitate the production of more robust and transparent estimates for both dimensions of young people's caregiving. It would yield figures for the numbers of young people with caregiving roles (a set of 'objective' estimates of the numbers of young carers across different age groups), and would produce a second set of estimates for the numbers who were 'vulnerable' – alongside a transparent rationale for how this vulnerability had been calculated (ie on the basis of lower scores for subjective well-being than the norm for peers) – and would, at the same time, permit a scrutiny of the benefits to well-being that some young carers may be deriving.<sup>72, 73</sup>

<sup>70</sup> Notwithstanding the fact that it excludes 18-25-year-olds - a group that have become significant in research, policy and practice circles in recent years - and that it continues to make an arbitrary distinction between those caring for a disabled, ill or incapacitated family member rather than the parallel care many young people provide to siblings, and often for economic reasons, as discussed earlier in the report.

<sup>71</sup> These have led to the development of better understanding of children's well-being as described in a series of reports published since 2010, most recently The Good Childhood Report, 2015.

<sup>72</sup> The inclusion of questions to measure physical and mental health could also allow for these aspects of young carers lives to be measured against their non-carer peers.

<sup>73</sup> At the time of writing the Department for Education had commissioned a fresh exercise to estimate the number of young carers. Its outcome will be eagerly anticipated by many in the field to see how the researchers have gone about creating a more credible estimation of the overall scale of young caring.

With these outputs this approach could also invigorate a young person-centred debate about caregiving, facilitating a better appreciation of the diverse outcomes young people experience, including the positive benefits reported by some.

Setting aside this consideration of the practicalities of better measuring young people's caregiving, the second project in the study looked into how the needs of young people with significant caregiving responsibilities might be better met – by asking a sample of young carers (who were engaging with specialist support projects in four areas) about how they understood and managed their caregiving responsibilities, how caregiving impacted on them, and what had helped or hindered them in accessing or engaging with services. Some of their parents and support workers were interviewed too.

What surfaced in the young people's accounts was the complexity of the issues involved and this highlighted that, just as with the challenge of 'measuring' young people's caregiving, 'assessing' the needs of young carers comes up against a diversity of circumstances which have many different bearings on the meaning of being a young carer and the heterogeneity of needs that flow from this.

Accentuating the challenge to professionals to comprehensively assess and respond to young carers is the associated problem of identification. This study showed, as others have before, that many of the most needy will be hard to reach or to engage, and also that many will not comprehend or will actively resist the label or status.

As a result, not only will appropriately assessing and meeting needs be challenging, especially for the more excluded groups, but even before this there will be significant initial barriers to locating and identifying young carers and their families.

Much progress has been made in recent years (including by the Government) to clarify the definition of a 'young carer'. However, given the evidence from this and other studies on the problems with the terminology around young people's caregiving – and the difficulties this brings for young people, families and professionals – it is clear that there is still work to be done on conceptualising and defining unpaid caregiving by young people.

It could also legitimately be argued that for young people who are disadvantaged in a variety of ways, caregiving is just one aspect of their lives amongst a set of other factors which are

shared with other non-carer, disadvantaged young people (such as material deprivation, parental neglect etc). For them caregiving may well not register as having any particular precedence – it may be just one of many ways in which society leaves their family to fend for itself.

Perhaps the most acute example of this is the young people who play a key role in a household by looking after younger siblings. For some this is because their non-disabled or ill parent is out at work and the other parent is incapacitated to the degree that they cannot adequately fulfil their parenting responsibilities – for others it is because the other non-disabled/ill parent is absent for other reasons (separation, bereavement etc). But regardless of the cause the young carer is performing a role that is principally underpinned by an economic imperative. And the degree to which their lives are different from a young person who looks after younger siblings purely because their parent(s) are out at work is difficult to distinguish.

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As a result many of the main messages on effective interventions to support vulnerable young carers mirror those which have been made before around supporting disadvantaged young people more generally. And, in reading these messages, it is also important to bear in mind that, even though the young people in this study were honest in sharing stories about the problems and stresses they had experienced as part of their caregiving role, many felt positive about it.

To overly problematise this aspect of their lives would not only do them a disservice, it would also underplay the significance of the other factors that are likely to be the principal causes of the difficulties they encounter.

'It's nice to be the one to support them and stuff – even though you can't really do anything about the situation...It makes me feel needed and wanted in the house. Before I never felt like that.'

**Alex, 15**



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## Appendix 1: Information on specialist projects who were involved in the research

		1	2	3	4 <sup>1</sup>	5	6	7 <sup>2</sup>	8 <sup>2</sup>	9 <sup>3</sup>	
<b>Age range</b>		14–25	0–24	8–18	0–18	8–18	8–18	8–18	7–25	5–18	
<b>No. of young people registered</b>		20	214 <sup>^</sup>	200	250	194	106	59	170 <sup>^</sup>	91	
<b>No. in the study</b>		3	6	5	4	9	7	2	5	3	
<b>Profile of service users</b>	<b>Ages</b>	<7	0	2%	0	2%	0	0	0	12%	4%
		8–11	0	18%	25%	36%	25%	26%	10%	35%	30%
		12–15	30%	36%	50%	34%	49%	44%	45%	18%	33%
		16–19	55%	30%	25%	28%	26%	29%	45%	24%	33%
		20+	15%	14%	0	0	0	0	0	12%	0
	<b>Ethnicities</b>	White	20%	89%	46%	–	88%	11%	35%	10%	14%
		Mixed	25%	4%	12%	–	7%	29%	20%	5%	12%
		Black	10%	2%	10%	–	2%	31%	20%	35%	44%
		Asian	30%	2%	18%	–	2%	13%	25%	45%	2%
		Other	15%	2%	5%	–	1%	1%	0	5%	2%
<b>Waiting list?</b>		No	No	Yes	Yes	Yes	Yes	No	No	Yes	
<b>Services provided</b>		Youth groups 1:1 support Day trips Counselling	Youth groups School outreach 1:1 support Day trips Family support Respite breaks	Youth groups School outreach 1:1 support Day trips Family support Respite breaks	Youth groups School outreach 1:1 support Day trips Respite breaks Counselling	Youth groups School outreach 1:1 support Day trips Family support	Youth groups School outreach 1:1 support Day trips Family support	School outreach 1:1 support Family support	Youth groups School outreach 1:1 support Day trips Family support	School outreach 1:1 support Day trips Family support Respite breaks* Holidays* Counselling*	

### Notes

<sup>1</sup> Project 4 was not able to provide data on ethnicity of young people (but had targets around ethnicity).

<sup>2</sup> Project 7 and 8 provided estimates of ethnic breakdown of young people (these are noted in italics in the table).

<sup>3</sup> Some of the services noted by project 9 were sourced through other agencies (denoted by \* in this listing).

<sup>^</sup> this was the number for whom the project could provide monitoring data – in both cases there were more young people registered with the projects but some had joined before monitoring systems were in place.

nb One participant was not involved with a young carer project at the time they were recruited to the research.

## Appendix 2: Methodology

### Researching the needs of young carers who are not accessing services: methodological challenges

The aim for the second project in this study was:

*'To explore the needs of particular groups among young carers who may not currently be benefiting from accessible, inclusive services. '*

Ideally, to meet this aim, a methodology for the project would have been used which investigated the needs of young people who had a caregiving role but who had either not been identified as a young carer, or who were not engaged with support services. This would have included an exploration of their needs and also of the reasons why they were not involved with a service.

Initial discussions about an appropriate methodology revolved around the possibility of recruiting and interviewing 'unidentified' or 'hidden' young carers. However, this raised a number of practical issues, including:

- the timescale for the fieldwork for the study, which did not lend itself to a potentially lengthy initial process of building networks with young people currently not in touch with services
- a condition that fieldwork needed to be conducted across four areas of the country (with a resultant significant impact on resource allocation).

There were also ethical implications of 'identifying' a young person as a carer through the research – eg this would bring with it a duty of care and, thereby, a need to be able to refer on to appropriate services to provide ongoing support.

Taking these considerations into account, a pragmatic methodology was developed which focused on interviewing young people who were already receiving some kind of formal support. To partially mitigate this, during early planning for the fieldwork for the study, a range of different projects and community groups were approached which were located in the study sites, in order to ascertain the feasibility of recruiting at least some young people to the research who were not benefiting from specialist young carer support. However, the only services to successfully provide potential participants were young carers services.

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As a result, this study concentrates on the experiences of young people who had already been formally identified as young carers and who were engaged with a young carers service. Only young people whose characteristics matched the three target groups were recruited to the interview sample.

Services were asked in particular to suggest young people who had recently joined a service to be interviewed; however in the majority of cases young people had been accessing the service for at least six months.

### Data collection for the second project

Research activity	Number of participants Target (Actual)
Survey questionnaire of specialist projects	9 (9)
Project-based interviews with young people	55 (40)
Self-completion questionnaire (for young people who were interviewed)	45 (41 <sup>^</sup> )
Two-stage interviews with young people	5 (5)
Interviews with parent(s)	5
Interviews with project workers	11 interviews completed (no target set)
Interviews with expert stakeholders	3 (5)

<sup>^</sup>Five of these were completed by young people from the family case studies

As noted above, a pragmatic approach was taken during fieldwork for the second project. The planned methodology – of conducting a short focus group with young people at a project (in theory only with those who had recently joined), followed by individual interviews with young people whose characteristics meant they fitted with the target groups for the study – had to be adapted ad hoc. For example, at some sites

young people had been transported to the venue in shared taxis and it was not possible for them to stay long enough to have individual interviews (in this case group interviews were done). The result of this was that the majority of interviews were done with small groups: 26 in small groups, four in pairs, and 15 in individual interviews.

However, the focus on young carers from the target groups was maintained in all interviews.

A subsample of five young people were re-interviewed two months after the first interview, with one interview happening during summer holidays, and one happening during the first term.

### **Appendix 3: Resources to support implementation of the Care Act 2014 and Children and Families Act 2014**

#### **The Care Act and Whole-Family Approaches**

##### **Association of Directors of Adult Social Services (ADASS) Carers Policy Network**

This document aims to provide practical guidance for practitioners working in adult social care in relation to carrying out assessments and developing plans which consider the needs of the whole family. It sets out best practice approaches to thinking 'whole family' in assessment, planning and review processes – as well as the combined legal framework with children's legislation that underpins this. It does not cover all aspects of the Care Act but is intended to assist practitioners to consider how to develop whole-family approaches in line with the new requirements. It also considers how the Act works in tandem with the provisions of the Children and Families Act to create a cohesive legislative framework that allows assessment and support for families to be combined where appropriate.

<http://www.local.gov.uk/documents/10180/5756320/The+Care+Act+and+whole+family+approaches/080c323f-e653-4cea-832a-90947c9dc00c>

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## No wrong doors: working together to support young carers and their families

### **A template for a local memorandum of understanding between statutory Directors of Children's and Adult Social Services – March 2015**

A resource to help promote working together between adult's and children's social care services and enhanced partnership working with health and third sector partners. This third edition reflects the important new duties and powers placed on local authorities by the Care Act 2014 and the Children and Families Act 2014. These obligations are reinforced in the Young Carers Assessments Regulations 2015, the Guidance related to both of these Acts and 'Working Together to Safeguard Children' (Department for Education, 2015).

The updated template offers a framework which professionals can use to provide personalised and joined-up support for young carers and their families.

<http://www.local.gov.uk/documents/10180/11431/No+wrong+doors+working+together+to+support+young+carers+and+their+families/d210a4a6-b352-4776-b858-f3adf06e4b66>

## Young Carers' Needs Assessment

### **Supporting information for use in conjunction with 'No Wrong Doors'; template for local memorandum of understanding on work with young carers**

This information was developed to provide supporting information for the Young Carers Memorandum of Understanding. It is intended to assist professionals working with young carers and their families, who may not have a background in children's services, to encourage a shared understanding of children's needs. The document was developed with substantial help from officials in the Department for Education (DfE).

<http://www.local.gov.uk/documents/10180/5756320/Young+carers+%20needs+assessment/d766543c-b933-4919-b020-97f43286a488>

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# It is a painful fact that many children and young people in Britain today are still suffering extreme hardship, abuse and neglect.

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**For more information on this report,  
please contact:**

**Phil Raws**

**Senior Researcher, The Children's Society**

**e. [phil.raws@childrenssociety.org.uk](mailto:phil.raws@childrenssociety.org.uk)**

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Names used in this report have been changed to maintain anonymity. All photographs posed by models.

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