

# Hidden from view:

The experiences of young  
carers in England



**By David Hounsell**

**Acknowledgements**

Many thanks to Lynne Woolley who produced the literature review that both supported the report and guided the data analysis. Also, many thanks to the Longitudinal Surveys Team at the Department for Education for their advice on using the Longitudinal Survey of Young People in England and for providing an initial review of the findings in this report. Any errors remain our own in entirety.

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## Foreword by Professor Saul Becker

This important study draws on government commissioned data on over 15,000 pupils aged 13 and 14. It examines how many of these children had caring responsibilities, the socio-economic characteristics of their families, young carers' educational attainment, and their chances of being in training or paid work. The size of the sample gives us confidence in the findings, many of which confirm earlier research but some of which are still shocking. For example, the data show clearly the differential impact that caring has on young carers compared to other children, including restricting their educational attainment in school and the knock-on effect that this can have on employment opportunities, careers and later life; the greater likelihood that, in contrast to other young people, young carers will not be in education, training or employment between the ages of 16-19; the reduced income that characterises many young carers' families (living on benefits, limiting disability, worklessness); and the stark finding that despite government rhetoric and advances in recognition and services for young carers over recent years, young carers are still no more likely than other children to be in contact with social services and educational welfare services - services that are mandated to offer them support.

The importance of the new data and analysis presented here is in its confirmation of existing findings about the personal and family circumstances of young carers, and especially the impact of caring on educational outcomes and employment opportunities. There can be no doubt that caring has significant impacts on many young people. So much so that they face disadvantages which not only affect their childhood and education in the here and now, but also cast a shadow forward and affect their futures and prospects in later life.

The recommendations presented here are simple, clear and achievable, given the right political will and the resources. We should not expect children to be relied upon to undertake caring which affects negatively their own development, well-being and education. We should expect service providers to be able to work across professional boundaries to assess and support the whole family, and for children and parents to be at the centre of decisions that affect them.

2013 is a time of policy and legislative opportunity as the government embarks on consolidation of key children's and adult legislation affecting young carers. I hope that the opportunity will be grasped by policy makers and practitioners, to strengthen young carers' rights and to deliver better outcomes for young carers and their families.

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## Section one - Introduction and key findings

There are 166,363 young carers in England, according to latest census data released on 16 May 2013<sup>2</sup>. The Children's Society believes this could be just the tip of the iceberg. Many young carers remain hidden from official sight for a host of reasons, including family loyalty, stigma, bullying, not knowing where to go for support. Some young carers are as young as five years old.

This report provides a valuable insight into the daily lives and outcomes for young carers, by using data from the Longitudinal Survey of Young People in England (LSYPE) publically for the first time. We know from our decades of experience of working with young carers across England, that caring can cost young people dearly if they are not given the opportunities to participate in all aspects of life. They can miss out on a huge range of opportunities that so many other children and young people take for granted, from educational opportunities, to spending time with friends and having time and space to do their homework.

It also reveals how young carers are gaining fewer qualifications and are therefore less likely to earn a decent living. We are calling for support for these children, to make sure that they have the same opportunities as other children. We hope to bring about change by influencing policy makers to help prevent these children and young people from caring in the first place.

Many young carers come from hidden and marginalised groups, including children caring for family members with mental illness or a substance dependency. This group of young carers was not captured in the latest census.

Children must be allowed to thrive and enjoy their childhoods, not be relied upon to take caring roles that are too often inappropriate. One young carer remaining under the radar, out of sight of the very authorities there to support them, is one too many.

### Young Carers in Focus

The Young Carers in Focus (YCiF) project is a four-year programme running until 2016, funded by The Big Lottery Fund and led by The Children's Society. It also brings partners together from YMCA Fairthorne Group, DigitalMe, Rethink Mental Illness and The Fatherhood Institute.

Many young carers come from hidden and marginalised groups, including children caring for family members with mental illness and parental substance dependency. This group of young carers was not captured in the latest census data. The YCiF partnership was formed to represent young carers from all walks of life. It aims to give them a voice and to highlight the issues they face. Find out more about the project on page 15.

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<sup>2</sup> Census 2011, Office for National Statistics - <http://www.ons.gov.uk/ons/rel/census/2011-census/detailed-characteristics-for-local-authorities-in-england-and-wales/index.html>

## Key findings

1. Latest census statistics reveal there are 166,363 young carers in England, compared to around 139,000 in 2001. This is likely to be an underrepresentation of the true picture as many remain under the radar of professionals.
2. One in 12 young carers is caring for more than 15 hours per week. Around one in 20 misses school because of their caring responsibilities.
3. Young carers are 1.5 times more likely than their peers to be from black, Asian or minority ethnic communities, and are twice as likely to not speak English as their first language.
4. Young carers are 1.5 times more likely than their peers to have a special educational need or a disability.
5. The average annual income for families with a young carer is £5000 less than families who do not have a young carer.
6. There is no strong evidence that young carers are more likely than their peers to come into contact with support agencies, despite government recognition that this needs to happen.
7. Young carers have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers e.g. the difference between nine B's and nine C's.
8. Young carers are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19.

### **The Longitudinal Survey of Young People in England (LSYPE)**

This report is based on new evidence on young carers from the LSYPE. The LSYPE was commissioned by the then Department for Children, Schools and Families (DCSF) as a major innovative panel study of young people. It began in 2004, with over 15,000 young people aged 13 and 14 completing questionnaires, and finished in 2010 with over 9000 young people in the original cohort still completing questionnaires.

The LSYPE therefore provides a rich source of information on young people's lives and their journeys through compulsory education and into adulthood. Of the 15,427 young people who completed the first wave, 689 (4.5%) said yes to the question, *'Some people your age may have to look after other people. This could be a brother or sister, a relative or someone else who is disabled or sick. Is there anyone like this who lives here with you that you have to look after on a regular basis?'*

The LSYPE study gives us rich data around young carers' circumstances, lives and outcomes. Our report presents analysis of the data specific to young carers, publically for the first time.

## Section two - The scale of the issue

### Who is a young carer?

To understand the scale of the issue, it is important to define clearly who is a young carer and who is not. The definition of who is a young carer has changed a great deal over the past decade. The agreed current definition, that considers the type of care and who is cared for, as well as the impact on the child or young person's life, was confirmed in recent national guidance:

*'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<sup>3</sup>'*

This definition was used to inform the literature review that supported this report and, where possible, the analysis of the LSYPE survey. It is important to note that this definition was not available when the first waves of the LSYPE survey were conducted. The question used in the LSYPE referred to *'disabled or sick'* as the descriptions to qualify a young person as a young carer, and therefore it is unlikely that young people with adults or siblings in the household who are misusing substances are captured in this analysis. There are also limited flags in the survey for *'excessive or inappropriate'* levels of care. The data analysis in this report presents the cumulative hours spent on caring responsibilities and the effect this has on school attendance as one perspective on level of responsibility; however it does not analyse the nature of caring responsibilities.

### How many young people have caring responsibilities?

Data from the 2011 Census, published on 16 May 2013, reveals that 166,363 children in England are caring for their parents, siblings and family members, an increase of 20% on the number recorded in the 2001 Census<sup>4</sup>. However, the Carers Strategy 2010<sup>5</sup> acknowledged that many young carers remain 'hidden' from health, social care and education services. This is partly because these services need to do more to identify them; but also because families fear that the children will be taken into care. Sometimes young people themselves are concerned about stigmatisation from others and bullying by their peers<sup>6</sup>.

The 2001 data from the census asked *'Do you look after, or give any help or support to family members, friends, neighbours or others because of a long-term physical or mental ill-health or disability, or problems related to old age?'* The

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<sup>3</sup> ADASS, ADCS and The Children's Society (2012), *Working together to support young carers and their families*, <http://www.adcs.org.uk/download/position-statements/2012/MoU%20young%20carers%202012.pdf>

<sup>4</sup> Census 2001, Office for National Statistics - <http://www.ons.gov.uk/ons/guide-method/census/census-2001/index.html>

<sup>5</sup> Department of Health (2010), *Recognised, valued and supported: Next steps for the Carers Strategy*

<sup>6</sup> Social Care Institute for Excellence [SCIE] (2005) Research briefing 11: The health and well-being of young carers <http://www.scie.org.uk/publications/briefings/briefing11/index.asp#users>

responses indicated that there were around 139,000 young carers under 18 years old in England<sup>7</sup>. The same question was used in the 2011 Census, which allows us to reliably compare the results.

However, this new census figure is still widely believed to not reflect the true scale of the problem. The census asked parents rather than children to complete the questionnaires and made no mention of the possible range of conditions where caring might be required, such as mental ill health, HIV and substance misuse. The Children's Society, and many other organisations, knows from our years of experience working with young carers, that many children remain hidden from the view of authorities they so desperately need support from.

In 2010, a BBC and University of Nottingham survey suggested there could be four times more young carers than the official census figures in 2001 showed<sup>8</sup> - approximately 700,000 young carers in the UK.

Although the LSYPE data cannot provide further estimates on the total number of young carers, as it only followed one cohort of year 9 pupils, we do know that of the young people who took part in the first wave of the survey, 4.5% identified themselves as having caring responsibilities. This would mean that 25,000 year 9 pupils<sup>9</sup> in England had caring responsibilities.

### **Tye's story – caring for his younger brother**

No two days are the same for 13 year-old Tye. They start and finish unpredictably, depending on how much he has to care for his seven-year-old brother.

Tye has three siblings. His youngest brother has Asperger's Syndrome – a form of Autism. This means his brother's behaviour can change throughout the day depending on how his routine goes.

They share a bedroom, so if his brother gets up very early, it wakes Tye. He then makes his brother's breakfast and helps him to get ready - before doing the same for himself. The early starts make it difficult for Tye to get organised for school and he can often be very tired during the day as a result. This makes the whole family late for school at times.

Tye helps to care for his brother to give his parents a break and because his little brother demands it. Tye would like to see his friends more often, but he can't. Most nights he has to go home to help look-after his little brother. They have such a close bond that he often only wants Tye to help, rather than another member of the family.

Tye feels frustrated at times and he would like to socialise like the rest of his friends. He also struggles to get space at home to do his homework. He feels he could put more effort into his school work if he had more time to do so.

<sup>7</sup> Census (2001) Office for National Statistics

<sup>8</sup> BBC (2010) Young carers are 'four times' the official UK number.  
[www.bbc.co.uk/newsbeat/11758368](http://www.bbc.co.uk/newsbeat/11758368)

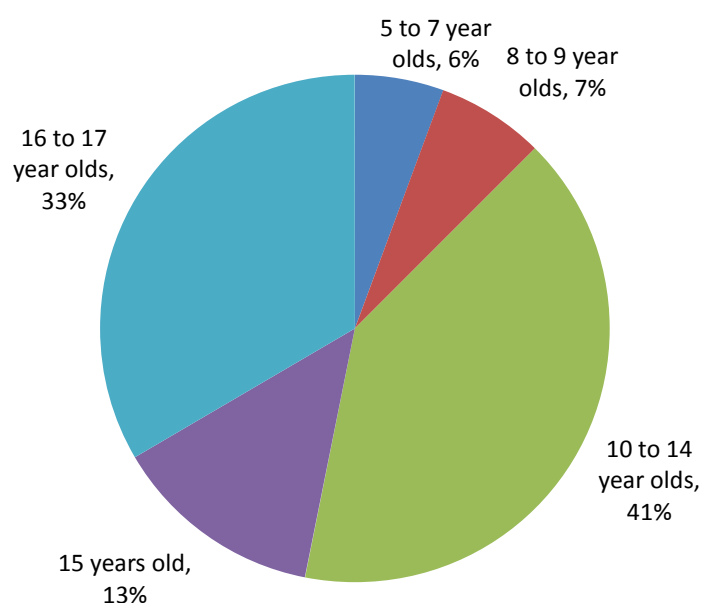
<sup>9</sup> Projecting onto latest pupil numbers - <https://www.gov.uk/government/publications/schools-pupils-and-their-characteristics-january-2012>

## Section three - The nature of caring

### Which young people are caring?

It is vital to know more detail about the nature of caring responsibilities, especially which young people are caring. As shown in figure 1 below, the 2011 Census showed a fairly even split between the number of young people caring who were aged between 10 and 14 (41%) and those aged between 15 and 17 (46%). This is similar with the findings from the previous census in 2001. However, one in eight young people caring were under the age of ten, which is an increase from 2001.

*Figure 1 – Age profile of young carers from the 2011 Census*



While the LSYPE data does not provide additional insights into the age profile of young carers, it does provide insight into other characteristics. The data show that young carers are:

- Equally as likely to be a girl or a boy
- 1.5 times more likely to have a disability, long-term illness or special educational needs
- 1.5 times more likely to be from a black, Asian, or minority ethnic community
- Twice as likely to not speak English as their first language.

The finding on young carers themselves having a long-term illness or disability supports the census data which showed that over 2000 young carers had bad or very bad health problems.

The finding that young people who are from black, Asian or minority ethnic communities are significantly more likely to be a young carer is striking, as it is in contrast to previous statistics. Previous research, and our own experience, has shown that young people from these communities are less likely to self-identify as young carers. They often do not recognise that they have taken on a caring



role by looking after their parents and siblings and may be less likely to know where to go to get help. This results in them regularly being underrepresented in statistics.

This section of the LSYPE survey was conducted through face-to-face interviews and it is possible that the survey method may have altered the young people's willingness to self-identify as a young carer. Further investigation of the effect of survey design would be required to understand this difference but this does again indicate the difficulty in accurately measuring the number of young carers.

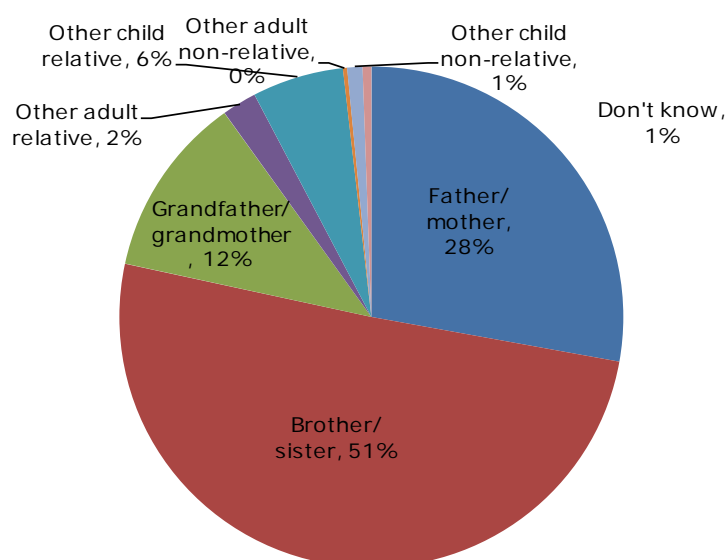
### Who are young people caring for?

Previous research has found that the person receiving care is often a parent, but can be a sibling, grandparent or other relative<sup>10</sup>. A survey of young carers<sup>11</sup> found that 66% cared for their parents, 31% cared for their siblings, 3% cared for their grandparents and 1% cared for wider family or community members. In addition, 10% of young carers cared for more than one person.

The LSYPE data actually points towards a greater proportion of young carers caring for their siblings and their grandparents than has been found in previous research. Figure 2 below shows the breakdown. Just over half of young carers were caring for their siblings, just under one in three were caring for their parents, one in eight were caring for their grandparents, and around one in 10 were caring for other relatives or non-relatives.

The LSYPE included young people who were not in contact with specialist young carer services. It may be that the young people who are providing care but are under the radar of services are more likely to be caring for their siblings.

*Figure 2: Who young people are caring for, using LSYPE data*



<sup>10</sup> Becker S. (2000). Young Carers, in The Blackwell Encyclopaedia of Social Work, ed. M. Davies. London, Blackwell.

<sup>11</sup> Dearden, C and Becker, S (2004) *Young Carers in the UK: The 2004 Report*, London: Carers UK and The Children's Society

## **Why are young people caring?**

Young people can have a wide range of caring roles and responsibilities<sup>12</sup>, including house work, healthcare, intimate personal care and wider tasks such as translating for non-English speaking family members or managing the family budget.

Whilst the LSYPE survey does not provide additional information about this, existing research has found that when asking young carers about the needs of the people they cared for, 50% said they were caring for someone with a physical health problem, 29% for a person with a mental health problem, 17% for someone with a learning difficulty and 3% for someone with a sensory impairment<sup>13</sup>. However the census does not ask whether the young person was caring for a family member with substance misuse issues, which increases the likelihood that the census figures are an underestimate.

## **How much caring do they provide?**

The level of caring responsibilities identified in the LSYPE varies substantially. Caring responsibilities can range from a few hours per week to over 100 hours per week in some extreme cases. Most young carers provide care for only a few hours each week; however for others the responsibility is excessive. The average number of hours the LSYPE cohort had to care for was three, with 62% of young carers caring for up to five hours each week. However, a further 30% of young carers were caring for between five and 15 hours each week, 5% for between 15 and 30 hours, and 3% for 30 hours or more.

This demonstrates that caring can take up a large amount of some young people's time, and sometimes this means that they miss school. Around 5% of young carers identified in the LSYPE said they missed school because of their caring responsibilities with one in three of those missing school doing so at least once or twice a month.

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<sup>12</sup> Dearden, C and Becker, S (2004) *Young Carers in the UK: The 2004 Report*, London: Carers UK and The Children's Society

<sup>13</sup> Dearden, C and Becker, S (2004) *Young Carers in the UK: The 2004 Report*, London: Carers UK and The Children's Society

## Section four – The circumstances affecting young carers' daily lives

We can use the LSYPE data to understand the circumstances affecting the daily lives of young carers. We used the data to look at household economic factors, parental characteristics, family structure, and young carers' contact with different agencies. Figure 3 below shows the factors that have a significant and strong association with being a young carer, in comparison with their peers.

*Figure 3 – Significant and strong associations<sup>14</sup>*

Factor	Relationship
Family income	The median family income for families including a young carer was £5000 less than families without a young carer
Adults in the household in work	Young carers are over four times more likely to live in a household where no adults are in work
Maternal education levels	Young carers are 1.6 times more likely to have a mother who has no educational qualifications
Adults with a limiting disability	Young carers are over twice as likely to live in households where at least one adult has a limiting disability
Number of children in the family	Young carers are 1.6 times as likely to live in households where there are three or more other children living

It is also important to note that in the areas where we may expect to see significant or strong associations, these did not exist. There is a weak relationship<sup>15</sup> between young carers and their level of contact with support agencies, including social services, educational welfare services and the police. This lends strength to the findings of the Carers Strategy 2010, that young carers remain 'hidden from view' of agencies, some of whom have explicit responsibility to identify and support young carers.

Analysis of the LSYPE also shows a weak relationship between young carers and the adults that they live with, with no strong evidence that young carers are more likely to live in lone parent households<sup>16</sup>. This is in contrast with the findings of a survey of young carers in 2004, which found that over half of young carers were living in lone parent families<sup>17</sup>.

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<sup>14</sup> Significant at the 1% level; non-trivial effect size

<sup>15</sup> Significant at the 1% level; trivial effect size

<sup>16</sup> Significant at the 1% level; trivial effect size

<sup>17</sup> 56% were living in lone parent families. Dearden, C and Becker, S (2004) *Young Carers in the UK: The 2004 Report*, London: Carers UK and The Children's Society

## **Section five – The effect on young carers' education and employment outcomes**

As highlighted in this report, the additional responsibility of caring for others can result in young people missing out on school. This is consistent with other surveys into the immediate impact of caring on young people's education. One survey found that 27% of all secondary school-aged young carers and 13% of all primary school-aged young carers experienced some problems relating to academic progress and attainment, and/or social interactions in school<sup>18</sup>.

Other studies have suggested an even greater impact. For example, a Barnardo's report found 43% of young carers felt their school work was 'adversely affected' by their caring role<sup>19</sup>, and a study with adults who had been young carers found that over 70% felt that their education had been significantly affected by their caring responsibilities<sup>20</sup>.

### **Effect on GCSE grades**

Missing school because of caring duties is likely to affect longer term education and employment outcomes. For example, within a small group of young carers aged 16-24 years old, a quarter had no GCSEs<sup>21</sup>. Research has also found that young carers may not reach their educational potential due to the disadvantages they face. This underachievement now affects their teenage and young adult life, restricting their opportunities and reducing the likelihood of them being a student, engaging in further education<sup>22</sup>, training or employment<sup>23</sup>.

Our new analysis of the LSYPE data adds weight to these findings. The average total GCSE points score for a young person who had caring responsibilities in year 9 was 333, compared to 386 for young people who were not young carers in year 9<sup>24</sup>. This is a difference of 53 points, equivalent to nine GCSE grades overall, or the difference between nine B's and nine C's<sup>25</sup>.

### **Effect on being in education, employment and training**

Research by the Audit Commission in 2010<sup>26</sup> found that young adult carers between the ages of 16 and 18 had a much greater chance of being not in education, employment and training (NEET). Of these, 75% had been NEET at least once (compared with 25% of all young people) and 42% had been NEET for six months or more (compared with 10% of all young people).

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<sup>18</sup> Dearden, C and Becker, S (2004) *Young Carers in the UK: The 2004 Report*, London: Carers UK and The Children's Society

<sup>19</sup> Barnardo's (2006) *Hidden Lives: Unidentified Young Carers in the UK*. Essex: Barnardo's.

<sup>20</sup> Frank, Tatum and Tucker (1999) *On small shoulders. Learning from the experiences of former young carers*

<sup>21</sup> Dearden and Becker (2000) *Growing up caring: Vulnerability and transition to adulthood – young carers' experiences* Foundation by the National Youth Agency

<sup>22</sup> Yeandle and Buckner (2007) *Carers, employment and services: Time for a new social contract?* Report No.6 University of Leeds and Carers UK

<sup>23</sup> Frank, Tatum and Tucker (1999), *On small shoulders: Learning from Experience of Young Carers*

<sup>24</sup> Where an A\* is worth 58 points, A=52, B=46, C=40, D=34, E=28, F=22, G=16

<sup>25</sup> Significant at the 1% level; non-trivial effect size

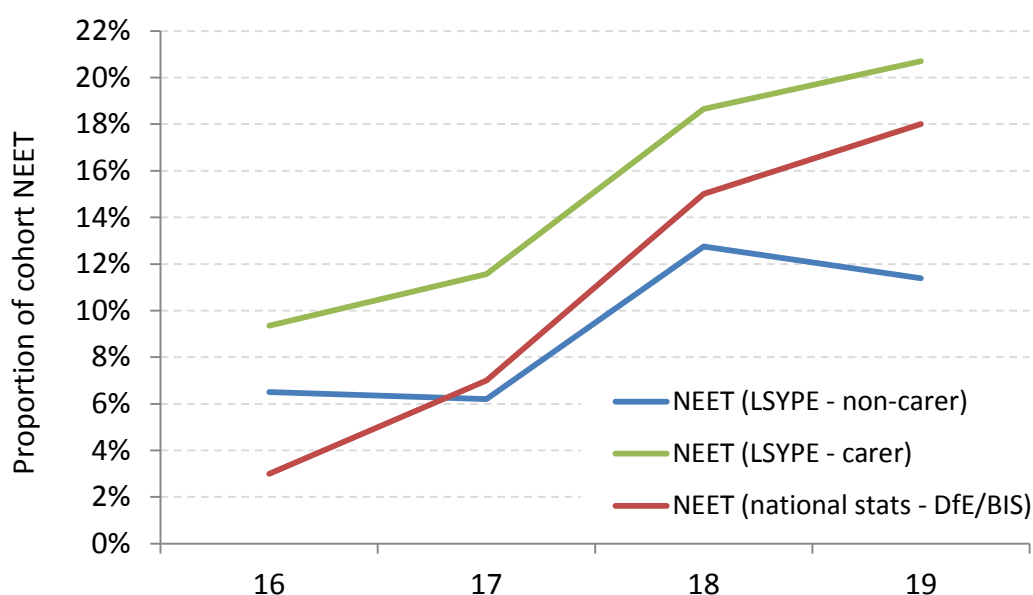
<sup>26</sup> Audit Commission (2010) *Against the odds: Targeted briefing – Young carers*. London: Audit Commission



Research with young adults has shown that on-going caring responsibilities mean that young adult carers are less likely to be in further or higher education. Among young carers aged 16-24, fewer than 16% of women and 21% of men who were caring for more than 20 hours per week were in education, in comparison to a 25% average for their peers with no caring responsibilities<sup>27</sup>.

The LSYPE data also shows a relationship, although not as strong<sup>28</sup>, between caring in year 9 and being NEET between 16 and 19 years old. Figure 4 below shows the difference in NEET profiles between the group of young carers and the group of young people without caring responsibilities at those ages. There is a one in three chance that a young carer in year 9 will become NEET between the ages of 16 and 19, compared to a one in four chance for those without caring responsibilities. Figure 4 also shows that the NEET profile for young carers is higher than the national profile.

Figure 4 – NEET profiles for different groups within the cohort



Being NEET between 16 and 19 years old has a huge impact on a person's outcomes later on in life. The Department for Education recognises that '*Being NEET is associated with negative outcomes later in life, including unemployment, reduced earnings, poor health and depression. These outcomes have a cost for both the individual and the economy.*'<sup>29</sup>

<sup>27</sup> Aylward (2009), Access to education and training for young adult carers. National Institute of Adult Continuing Education

<sup>28</sup> Significant at the 1% level; trivial effect size

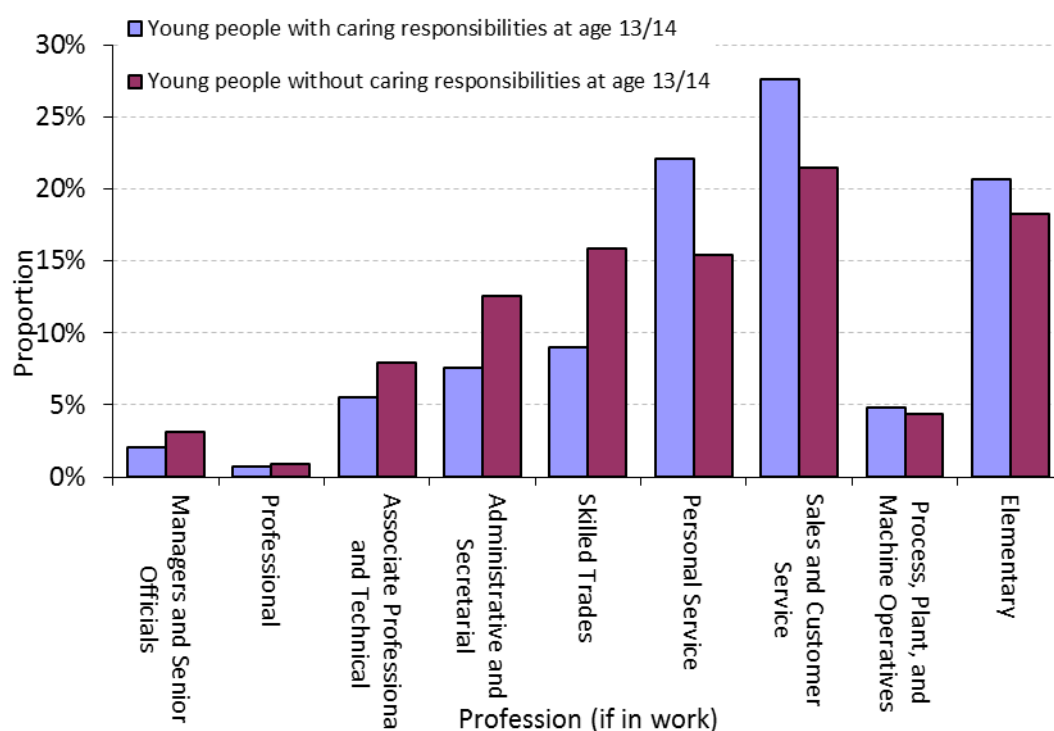
<sup>29</sup> Department for Education (2013),

<http://www.education.gov.uk/childrenandyoungpeople/youngpeople/participation/neet>

## Effect on early employment

The LSYPE data also shows that young carers in work at age 20/21 are more likely to be in lower skilled occupations, although again this is not as strong as the GCSE link<sup>30</sup>. Figure 5 below shows that young carers are more likely to be in professions such as personal service, sales or customer service occupations than their peers, and less likely to be in managerial, associate or skilled trade roles than their peers. Young carers are sometimes influenced by the skills gained through their experiences, for example, applying for work in the 'caring professions'<sup>31</sup>.

*Figure 5 – Occupations for young people who were in employment at age 20/21 for different groups within the cohort*



This section of the report demonstrates a significant association between young people caring in their mid-teens and lower educational attainment by the age of 16. There is also a clear association between being a young carer and having lower job prospects and educational opportunities between 16 and 19, and between being a young carer and the likelihood of being in lower skilled occupations at age 20/21. This evidence provides a strong rationale for tackling the problem of young people taking on a caring role during their teenage years.

<sup>30</sup> Significant at 10% level; trivial effect size

<sup>31</sup> Dearden and Becker (2000) Growing up caring: Vulnerability and transition to adulthood – young carers' experiences Foundation by the National Youth Agency

## Section six – What can be done about it

The government's Carers Strategy 2010 laid down a marker for the support that young people with caring responsibilities should be entitled to. *'Children and young people should be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods'.*

The analysis in this report shows that the additional responsibilities that come with being a young carer can have a detrimental effect on their education and employment outcomes. In this section, we focus what can be done to improve the situation.

### 1. The Young Carers in Focus partnership

It is vital that young carers are supported to have the same education and job opportunities and leisure time as other children who are not carers. These young people should also have a voice, to raise awareness about the true scale of the problem of children taking on inappropriate caring roles in England.

The Young Carers in Focus (YCiF) partnership, led by The Children's Society and funded by the Big Lottery Fund, is giving young carers a voice, and the recognition and support they so desperately need to generate public awareness opportunities and improve public understanding about the issue. It brings together partners from Rethink Mental Illness, The Fatherhood Institute, DigitalMe and YMCA Fairthorne Group.

YCiF aims to recruit more than 200 young carers 'champions' over four years to attend workshops and training to gain skills, resilience and confidence. They will be supported to advocate at a national and local level to raise awareness and make positive changes to the lives of young carers across the country. In addition, thousands more young carers from across the England will run and participate in a safe social media page, hosted by the [www.makewav.es/ycif](http://www.makewav.es/ycif) platform running safe social media in schools.

The Big Lottery funding will enable partners to work towards meeting these outcomes:

- Children and young people are protected from taking on inappropriate caring roles that negatively impact on their own education, physical and emotional health, leisure time and future life chances.
- Young carers and their families are supported to get their voices heard to inform policy and services on a national and local level.
- Young carers are supported to have the same opportunities to education, employment, training and leisure time, particularly at points of transition, as their peers.
- There is improved public awareness and understanding of family illness and disability to promote positive attitudes towards young carers and their families and mitigate the impact of stigma and discrimination.

Local authorities, schools, GPs and young carers' services can support the work of the project by referring young carers to the safe social network, by engaging

with their local 'champions'. and by visiting the site to gain an insight into the issues these young people face.

The Children's Society has also been funded by the Department of Education to deliver England-wide training to local authorities. This is to assist children's services and adult social care to work in partnership to deliver a 'whole-family approach' to localised delivery. To support the whole family, every time an adult's needs are assessed, the needs of children in the family should also be considered, to prevent them taking on inappropriate caring roles.

### **Kelly's story – looking after her mum with anxiety issues**

I live at home with my mum Fiona and younger sister Samantha. Mum has anxiety issues, panic attacks and takes medication for depression.

My job is to reassure her that everything is ok. She gets really anxious and does this horrible routine every night before she goes to bed to make sure everything is switched off and locked. She also switches off each light in the house saying: 'Off! Off! Off!' But if her finger slips, she will do it all over again. She's usually in bed by 9pm after taking her medication for depression, leaving me in charge.

One day she left the gas cooker on, which could have set the house on fire. After she turned it off one time, she accidentally nudged the gas knob on again. She also once left the chip pan on, which was really scary.

She copes with her anxiety by sleeping during the day as it helps her stop worrying. But it doesn't stop me worrying. I don't feel anyone really understands what I have to go through or how anxious I often feel. Looking after my mum and sister is a constant worry and I have to rush home every day after college to make tea, clean and shop.

Because mum's frightened of leaving the cooker on I do all the cooking and help out with the housework. Mum's too scared to go out alone so I have to take her everywhere which leaves me little time to spend with my friends.

My sister's 15, but she's really young for her age so I feel responsible for her too. One thing that really helps is the support I get from the young carers centre. They understand what it's like; I can trust them and talk about my problems knowing that I won't get judged. The school drop-in centre is also great. Looking after mum has inspired me to change from my current course on mechanics to study health and social care at university.

\*Kelly is supported by Crossroads Care in Gateshead

## **2. Consolidating adult and children's legislation on young carers**

Currently, the legal framework for young carers is complex and confusing and acts a barrier to good practice. Children are often not 'seen' as part of an adult's assessment for support and disabled adults not recognised as parents. This



means that children are not identified as young carers and therefore miss out on the vital support they need.

As a member of the National Young Carers Coalition, The Children's Society wants to see a legal framework that ensures that children are prevented from undertaking inappropriate caring and adults' needs for care and support are met.

2013 provides a unique opportunity to consolidate key adult and children's legislation affecting young carers, making sure agencies work effectively together to support families with young carers – identifying them, assessing their needs and providing the necessary support to the whole family.

The Care Bill and the Children and Families Bill are both going through parliament. This gives us a once-in-a-generation opportunity to remove the barriers to good practice, to prevent children's needs escalating or safeguarding issues arising, and to reduce costs in the long term.

### **3. Financial support for families with young carers**

The changes included in the Welfare Reform Act and its supporting regulations will impact greatly on the income of families with young carers.

One of the proposals is to remove a key element of support, the severe disability premium (SDP). Currently the SDP gives additional support to disabled adults who receive a component of Disability Living Allowance and live on their own, or with children, and no one is paid carer's allowance for assisting them. This additional support helps to cover the additional costs of both living alone with a disability and having no carer. For disabled parents, receiving the premium can help reduce the pressure on their children, often of school age, to care for them. This change could cost a family with a young carer up to £58 per week, or around £3000 per year<sup>32</sup>.

In addition there are also changes to the enhanced disability premium (EDP), which provides extra help for the most severely disabled adults. This, on top of changes to the SDP, means that around 25,000 families with a young carer looking after a disabled parent could lose up to £73 per week, or around £3800 per year<sup>33</sup>. This may result in more children being expected to take on more caring responsibilities.

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<sup>32</sup> The Children's Society (2012), [http://www.childrenssociety.org.uk/sites/default/files/tcs/citizens\\_advice\\_report\\_2012-3.pdf](http://www.childrenssociety.org.uk/sites/default/files/tcs/citizens_advice_report_2012-3.pdf)

<sup>33</sup> Gingerbread and The Children's Society (2013), [http://www.childrenssociety.org.uk/sites/default/files/tcs/u56/single\\_parents\\_and\\_universal\\_credit\\_singled\\_out\\_final\\_0.pdf](http://www.childrenssociety.org.uk/sites/default/files/tcs/u56/single_parents_and_universal_credit_singled_out_final_0.pdf)

## Section seven – Conclusion

This report lifts the lid on the realities of being a young carer. Building on existing research, this report highlights that many young people are taking on excessive or inappropriate caring responsibilities. This is having a major negative impact on their childhoods - and on the rest of their lives.

Latest census data shows just how many children – 166,363 in England alone – are officially caring for their parents, siblings and family members; some are as young as five years old. However, The Children's Society and other charities involved in the Young Carers in Focus (YCiF) believe this figure does not reflect the true scale of the problem. Too many children remain hidden from the view of authorities.

New analysis shows that young carers are more likely than their peers to come from a poorer background, have a special educational need or a disability, and come from black, Asian or minority ethnic families. Young carers deserve the same rights to education and a decent job as all young people. However, as Hidden from View shows, inappropriate or excessive caring is having a negative effect on their school life and that they are missing out on having a social life and getting decent qualifications and jobs.

The growing body of evidence underlines just how vital it is that these children and their families receive the professional support that they so desperately need. Three key pieces of legislation affecting the lives of young carers will be debated and passed during 2013. They provide a unique opportunity for the government and support agencies to look again at the support young carers and their families are receiving.

Over the next four years, the Young Carers in Focus partnership (YCiF) will empower more than 200 young carers across England to have a voice to call for change, to share their experiences and to raise awareness about the issues they face, and will reach out to thousands more via the social media platform [www.makewav.es/ycif](http://www.makewav.es/ycif).

This new analysis provides compelling evidence that young carers need significantly more support to make sure that they do not lose their childhoods to caring. The Children's Society is playing a leading role in providing young carers with a voice on key decisions that affect them, with the YCiF partnership playing a key national role over the next few years. All children must be allowed to thrive and enjoy their childhoods. One young person remaining under the radar, out of sight of the very authorities there to support them, is one too many.

## About us

The Children's Society has over 130 years' experience of supporting society's most vulnerable children and young people. We work directly with these children, many of whom have nowhere else to turn, to ensure that they are loved, valued and listened to.

## Our work with young carers

Thousands of children across the country are forced to grow up early and miss out on vital educational and recreational opportunities because they care for disabled or chronically ill adults or younger siblings. We campaign for change and promote best practice with central and local government and work in partnership with social workers, teachers and health care professionals to deliver solutions that consider the needs of the whole family.

For further information about the findings and methodology please contact David Hounsell, Economic Advisor, on [david.hounsell@childrenssociety.org.uk](mailto:david.hounsell@childrenssociety.org.uk) or **07713 101884**

For further information about the Young Carers in Focus Partnership please contact Jenny Frank, Programme Manager The Children's Society's Include Project, on [jenny.frank@childrenssociety.org.uk](mailto:jenny.frank@childrenssociety.org.uk) or **01962 711511**

[www.childrenssociety.org.uk/young-carers](http://www.childrenssociety.org.uk/young-carers)

## Young Carers in Focus (YCiF)

The YCiF project is a four-year programme, funded by The Big Lottery Fund and led by The Children's Society which brings together the following partners:

**digitalME**  
New Directions in Learning

**YMCA**  
Fairthorne Group

fatherhood  
INSTITUTE

**makewaves**

