



# Still Hidden, Still Ignored

Who cares for young carers?

By Emma James, December 2017

Believe in  
children  
 Barnardo's

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# 1. Introduction

*'Low self-esteem, lack of understanding of complexity of feelings, lack of protective factors, feeling of not being able to cope' (Barnardo's young carer Practitioner talking about the impact of caring on young people.)*

As adult social care becomes more squeezed and thresholds for support are higher than ever, more and more young people are providing care in the home to their relatives (predominantly parents) than ever before. This relative may have a physical disability; a long-term illness; emotional and mental health problems; or drug/alcohol dependencies. The care they provide ranges from administering medicines, washing and bathing, cooking, financial management and emotional support. It also often incorporates taking care of siblings. The impact the responsibility of this care can have on a young person is profound and long-lasting, and outcomes for these children are significantly lower than their counterparts.

Eleven years ago, Barnardo's undertook an in-depth research study into why so many young carers were remaining unidentified and unsupported in the UK. The report *Hidden Lives, Unidentified Young Carers in the UK* found that there was a culture of secrecy amongst young carers and their families, and that the support available from schools and agencies working with them was inconsistent and often unsuitable. As the report concluded *'Many (young carers) spend years unidentified, unsupported and isolated in their caring responsibilities'*.<sup>1</sup>

Over a decade later with significant changes in policy along the way, many young carers are still being failed by the numerous agencies they come into contact with. Some are not being identified and are not receiving the targeted and consistent support they so desperately need. It continues to be hit and miss as to whether schools are aware of the reality of their situation and are equipped to putting safeguards in place to ensure there is a whole school approach to offering support.

Drawing on research conducted with our service practitioners, teachers and young carers themselves, this report makes a number of policy and services recommendations. What underpins these recommendations is that the responsibility of effectively identifying and supporting young carers needs to be solidly ingrained in all agencies. Clear pathways must set out for practitioners both working with adults and children to ensure that these children and young people do not continue to be failed and forgotten. **A full list of recommendations for change can be found in Appendix 1.**

## 1.1 Executive Summary

Child labour is the employment of children in any work that deprives children of their childhood, interferes with their ability to attend regular school, and that is mentally, physically, socially or morally dangerous and harmful. This practice is considered exploitative and there is much legislation across the world that prohibits it. While caring for family members is not classed as child labour, it can have similarly damaging impacts on a child's development, attainment and mental health.

Many children across the country are undertaking in excess of 15 hours a week of caring for a family member. We believe that there has been an increase in the number of young carers as more and more families struggle to access external support. Analysis by the Office of National Statistics in July 2017 showed that unpaid carers save the UK economy almost £60 billion a year.<sup>2</sup> The report goes on to say that the value of unpaid care outweighs the amounts spent on formal social care. Although these statistics refer to adult carers, we have no doubt that more and more children are also feeling the burden of these cuts. Back in 2010, Maggie Atkinson, the then Children's Commissioner for England, told the BBC that child carers "save the state millions" and many of them "lose their childhoods"<sup>3</sup> due to their roles within the home.

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1 Hidden Lives, Unidentified Young Carers in the UK – Barnardo's, 2006.

2 <http://www.bbc.co.uk/news/uk-36234501>

3 <http://www.bbc.co.uk/news/education-11757907>

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It is little surprise that families with young carers on average have a family income £5000 lower than families without and are more likely to be single parents. These families will often already experience multiple adversities. Their struggles become placed on children's shoulders which can have a significant impact on their long-term outcomes.

The Children and Families Act and the Care Act 2014 provided a welcome opportunity to address the lack of legislative provision for young carers. The National Young Carers Coalition (NYCC)<sup>4</sup> succeeded in their campaign to change the law and local authorities now should take reasonable steps to identify young carers in their area, assess them for support and ascertain what type of support needs they have.

Barnardo's long experience of working with young carers puts us in a good position to assess the impact this change in legislation has really had on the lives of young carers over its first three years. Over 4,000 parents and children accessed Barnardo's 21 specialist young carer services in 2016/17. In addition, many young carers access other Barnardo's services such as advocacy, edge of care and domestic abuse services.

This hard-won legislation has had a positive impact on identification. But the funding has not kept pace with the increased number of referrals and too many young carers are still sacrificing opportunities even after local authorities are aware of their situation. There will always be young carers, but with proper support and guidance they don't have to trade off their future to help those they love. It is time that local authority commissioners and all relevant stakeholders prioritised the needs of those who at such a young age are making huge sacrifices for their loved ones.

Though Barnardo's joins others in celebrating the selfless and considerate young people who, all over the UK, are caring for their loved ones over their own needs, all too often this is used as an excuse for inaction. The reality of young carers today is young people in their thousands sacrificing their future and their mental health to cover cuts in social care and without any responsibility being taken for them by the statutory agencies involved.

## 1.2 Research Methods

Barnardo's partnered with YouGov to undertake a survey of over 800 teachers in Sep and Oct 2017 to give a full picture of the reality for young carer support in schools.

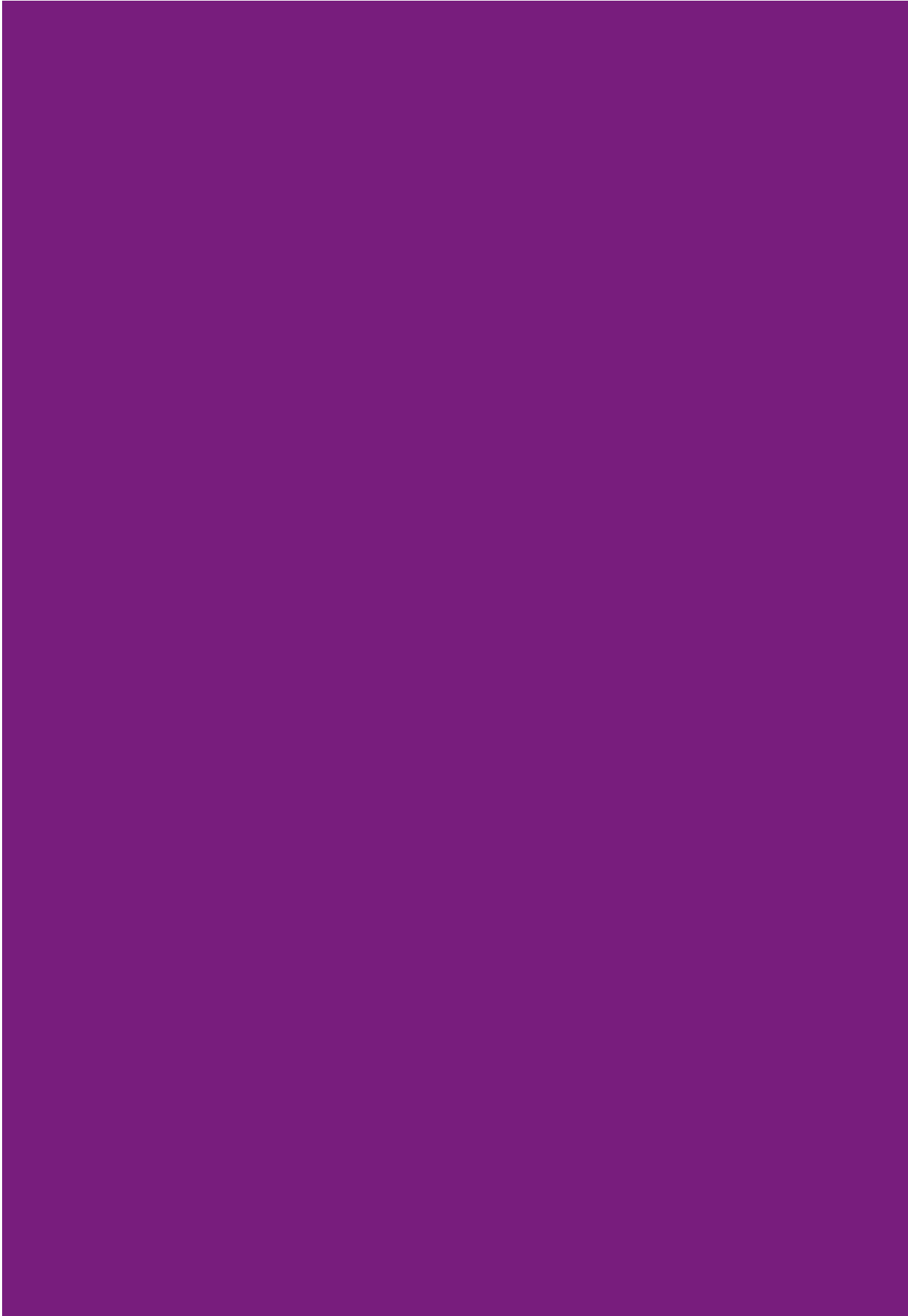
Barnardo's also undertook interviews and in-depth surveys from over 40 Barnardo's Young Carer Practitioners who work across our 20 Young Carer Services in England. We then directly surveyed 79 young carers who have been using Barnardo's services in England aged between 7-24 years old. The surveys covered a range of issues from support needs, school support, legislation change and identification and provided both qualitative data and quantitative evidence.

In addition, Barnardo's held focus groups with young carers aged between 9-25 in Preston, Newcastle and Liverpool and interviewed practitioners and service managers in these areas.

**A summary of the key research findings can be found in Appendix 2.**

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<sup>4</sup> A coalition of organisations including Barnardo's concerned with young carers and their families.



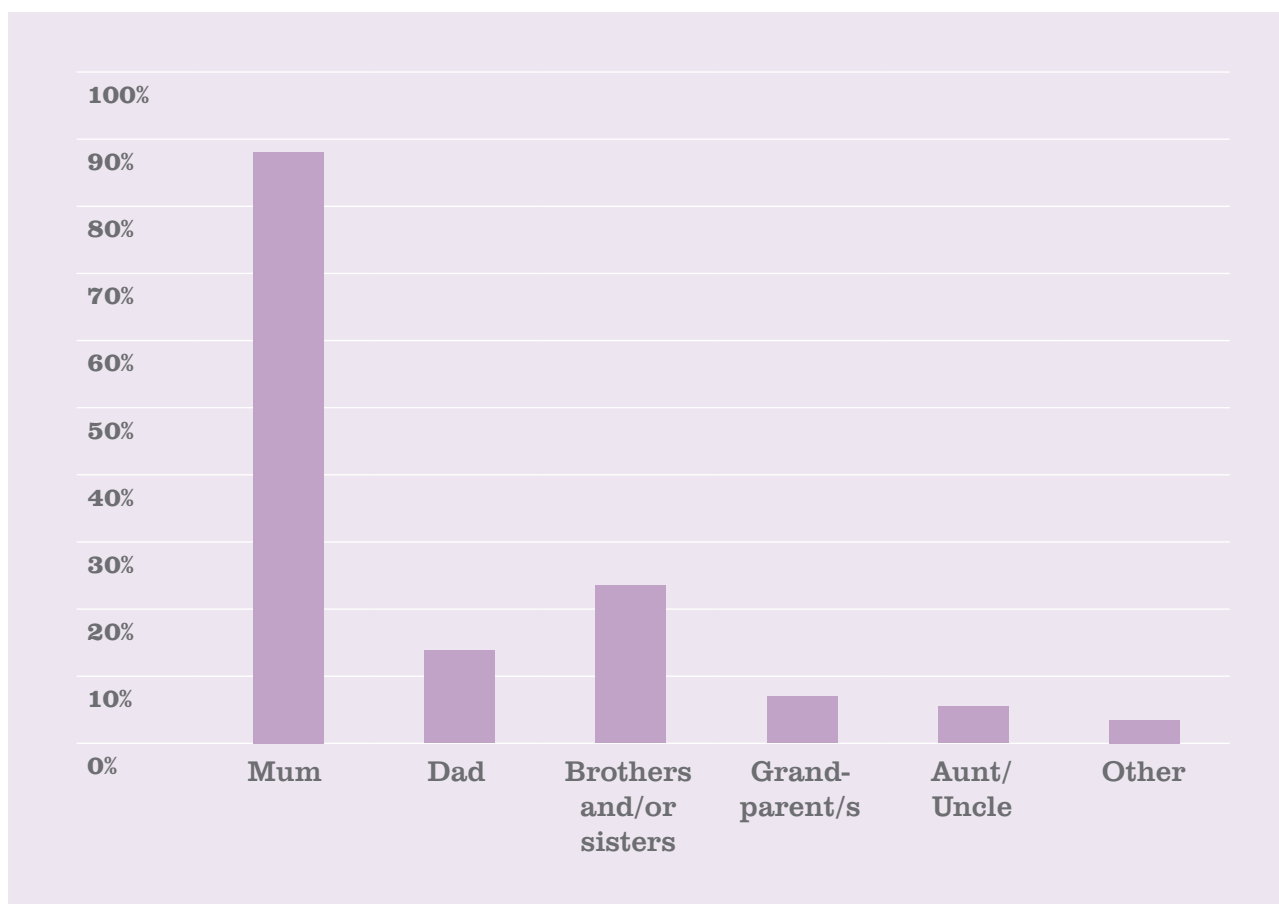
## 2. Context

### 2.1 Who are young carers?

Statutorily, a young carer is defined as a 'person under 18 who provides or intends to provide care to another person'. This includes 'providing practical or emotional support' which is 'not under or by virtue of a contract or of voluntary work' (Children and Families Act, 2014) More broadly, a carer is 'somebody who provides support or who looks after a family member, partner or friend and who needs help because of their age, physical or mental illness or disability' (Care Act, 2014).

Young carers look after a relative who has a condition, such as a disability, illness, mental health condition, or a drug or alcohol problem. Most young carers look after one of their parents or care for a brother or sister. Nearly 45% told us they also looked after their siblings. A clear majority of Barnardo's young carers indicated they were caring for their mum as shown in the table below and because of this will often care for siblings too.

**Table 1: Who do young carers care for?**



According to the 2011 census there are around 195,000 young carers in the UK. The census did not include those who care for family members with drug and alcohol problems in their estimate. In addition, the

numbers rely on families to self-declare which many are hesitant to do as they fear further consequences. As well as this, the term 'young carer' is not always familiar to families and many do not understand or

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equate this term with their situation. In 2010, research from the BBC and the University of Nottingham put the number as closer to 700,000.<sup>5</sup> Professor Saul Becker, Head of the School of Sociology and Social Policy at the University of Nottingham, said at the time that the survey pointed to a “hidden army” of young carers in the UK.

The BBC survey cited above estimated that about 1 in 12 secondary aged pupils have caring responsibilities. The census statistics show that the number of 5-7 year olds providing care increased by 83% between 2001 and 2011<sup>6</sup> although as mentioned this number is likely to be much higher.

**Gender** – Unpaid carers across all ages are slightly more likely to be female (58% female, 42% male). Our young carers’ survey respondents were 2:1 ratio female to male. However, the 2011 census data put male to female ratio at 50:50.

**Ethnic Minorities** – Carers UK in an October 2015 Policy Briefing found that Black, Asian and Minority Ethnic Carers were less likely to receive support both financially and practically, often as a result of the difficulty in accessing culturally appropriate information and a lack of engagement with these communities.<sup>7</sup> Alongside this, the

Children’s Society stated in their 2016 report *There’s nobody is there – no one who can actually help?*<sup>8</sup> that BAME young carers were ‘hidden’ from services. This is particularly worrying when according to the 2011 census, young carers are 1.5 times more likely to be from these communities and twice as likely to not have English as their first language.

**Disability** – Data from the 2011 census showed that young carers are more likely to have a disability, long-term illness or special education needs.

## 2.2 What type of caring do they do?

Their day-to-day responsibilities often include cooking; cleaning; shopping; providing nursing and intimate personal care; giving emotional support; financial management; and caring for siblings. They can even be a crucial communication link by being the primary translator in a non-English speaking family. Data from our young carers’ survey shows how the majority of respondents said that as well as undertaking physical tasks they also provide emotional support to the person they care for. Other high responses included shopping, going to GP appointments and doing the cleaning and washing.



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<sup>5</sup> <http://www.bbc.co.uk/news/education-11757907>

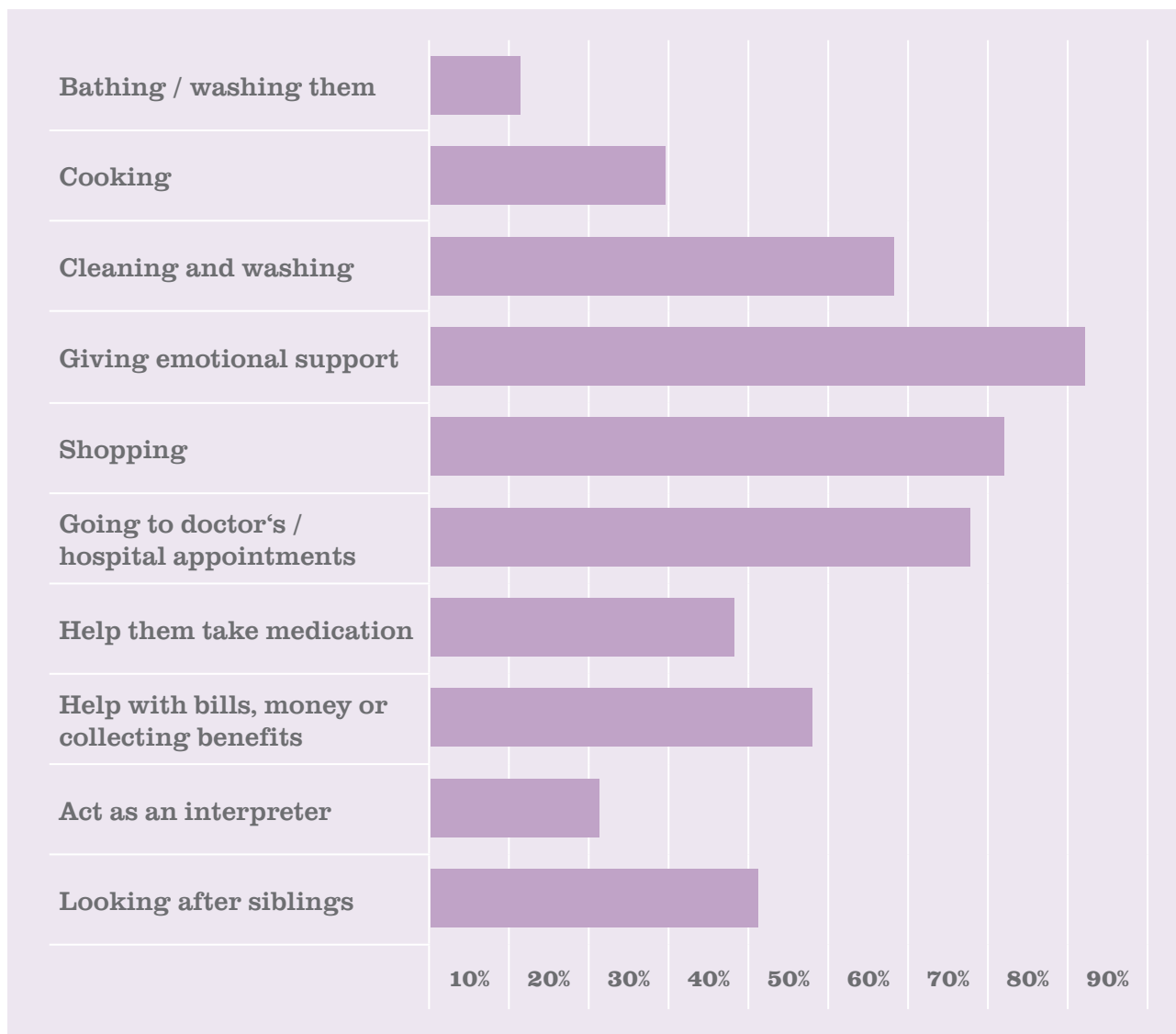
<sup>6</sup> <http://www.bbc.co.uk/news/education-11757907>

<sup>7</sup> [https://www.carersuk.org/images/Facts\\_about\\_Carers\\_2015.pdf](https://www.carersuk.org/images/Facts_about_Carers_2015.pdf)

<sup>8</sup> There’s nobody is there – on one who can actually help? The challenges of estimating the number of young carers and knowing how to meet their needs The Children’s Society, 2016.



**Table 2: Types of care young carers provide. These tasks are undertaken on top of their school commitments and academic work and often in addition to part time jobs to financially support the family.**



### What condition does the cared for person have?

90% of respondents were caring for someone with a physical disability, a mental health issue or a long-term health issue. Whilst the number of young carers who are caring for someone with a physical disability is high (50%) the number caring for someone who suffers mental ill health is even higher (55%).

As the Carers Trust noted in their report *Invisible and in distress: prioritising the mental health of England's young carers*, young carers often cite not having access to information about the condition and needs of the person they care for as an added worry and stress factor.<sup>9</sup> Barnardo's practitioners agreed and stated that the voice of young carers needs to be included more in discussions with professionals about the person with care needs condition and support plan. This is referenced further in Section 5 – Relieving the Burden of Care.

<sup>9</sup> Invisible and in distress: prioritising the mental health of England's young carers, Carers Trust 2016.

**Table 3: The difficulties suffered by the person young carers are caring for.**

Physical disability (e.g. sight or hearing problems, in a wheelchair, mobility)	<b>50.63%</b>
Mental ill health (e.g. depression, OCD, agoraphobia, anxiety, bipolar, etc.)	<b>55.70%</b>
Problematic use of drugs and/or alcohol	<b>10.13%</b>
Long term illness (e.g. MS, fibromyalgia, cancer, heart problems)	<b>36.71%</b>
Learning disability (e.g. ADHD, dyspraxia)	<b>6.33%</b>
Rather not say	<b>2.53%</b>
Other	<b>13.92%</b>

## 2.3 Age & Time Spent Caring

### Age started caring

Using the census statistics, the average age of a young carer in the UK is 12, with some children as young as four caring for members of their family.

One strong feature of the respondents from the young carers supported by Barnardo's is the age they started providing care. 12% of respondents had started caring by the age of five and two thirds of the young carers started while they were still in primary school. There were however, a number both from the survey and in the focus group who started caring in their teenage years. Many of them told us that they actually believed that older young carers found it difficult to access support as teachers often disregarded their calls for help and they found it difficult to navigate a system they were unfamiliar with.

A striking finding from our survey of practitioners across Barnardo's is that 100% of respondents had received referrals for

young carers who were under the age of eight, indicating young carers are starting caring from a young age across the country. Unfortunately there is very little support provision available for this age group.

### Hours spent caring

In 2004, Saul Becker and Chris Dearden undertook a major study of young carers in the UK surveying over 6000 young carers from 87 projects. The report found that almost half of the young people were caring for ten hours or less per week. However, a third cared for between 11 and 20 hours per week and 18% cared for more than 20 hours per week. Becker also conducted secondary analysis of the 2001 Census data of young carers. Becker calculates that nationally 84% of young carers spent between one and 19 hours per week caring. In the 2004 survey reported here, 82% of young carers were caring for 20 hours or less per week. Becker's analysis suggests that 9% of young carers nationally care for 20 to 49 hours and 7% for 50 hours or more. In this sample 16% were caring for 20 to 50 hours per week but just two % for over 50 hours.<sup>10</sup>

In 2013, The Children's Society stated in their *Hidden from View* report that in England, one in 12 young carers spend more than 15 hours a week looking after a parent or sibling.<sup>11</sup>

The Department for Education's 2017 young carers study *The Lives of Young Carers in England* analysed the number of hours spent caring and differentiated between weekends, school holidays and a school week. Most young carers spent more time caring at the weekends and during holidays than during the school or college week. But still, at least one in seven (14%) of all young carers were providing care for more than four hours a day on top of their studies. At weekends and holidays, this rose to over one in four (26%).<sup>12</sup>

In our survey, young carers were asked if they could estimate the number of hours a week they spent caregiving. Although nearly 27% did not know how many hours they spent caring, over 25% (20 young carers) said that they undertook over 30 hours of caregiving a week. Over 30% of the young carers spend over 20 hours per week providing care – more than half of a full-time job.

10 Young Carers in the UK, the 2004 Report – Saul Becker and Chris Dearden.

11 Hidden from View 2013 The Children's Society.

12 The Lives of Young Carers in England, January 2017, DfE Sarah Cheesbrough, Carrie Harding, Hannah Webster and Luke Taylor – Kantar Public With Professor Jo Aldridge - Young Carers Research Group - Loughborough University.

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## 2.4 Legislative Framework

*'It is most definitely positive progress that young carers are identified in legislation however I do believe that by making it 'everybody's business' it has almost become nobody's business. local authorities need to take true ownership over the young carers' agenda and ensure that the necessary frameworks are embedded in statutory service'. (Barnardo's young carers practitioner)*

As already highlighted, the legislative framework has changed significantly since our 2006 *Hidden Lives* report. The Children and Families Act 2014 and the Care Act 2014 places a statutory duty on local authorities to take 'reasonable steps' to identify young carers in order for them to have a needs assessment. Barnardo's young carers practitioners, some of whom have worked with young carers for over fifteen years, told us how the change in legislation has impacted both their service and how young carers are supported.

We surveyed Barnardo's practitioners on the impact three years on. They reported that the right to an assessment secured in legislation has raised the profile of the need for young carers services with commissioners and other agencies and raised awareness. Specifically:

*'Awareness of young carers has improved and legislation has provided the rights to an assessment. More follow up from the introduction of the Care Act is needed to measure the difference made and the journey travelled'.*

*'Support has improved and the numbers has definitely increased'.*

*'The Care Act prompted the borough to start a task and finish group to develop the protocol for young carers. This has increased the number of referrals'.*

*'There is a greater awareness of young carers. Emotional support for young carers has increased and there are stronger assessments of young carers needs'.*

*'The Children and Family Act 2014 which I continually raise professionals' awareness of. This seems to make people listen a little more'.*

However, many practitioners reported that although numbers being assessed and identified were increasing, in some areas this had led to a reduction in support. In particular:

*'Increased numbers and identification is a positive impact and gives us the ability to make reference to legislation when advocating for support. Now the concern is that some local authorities are taking this support in-house and are just providing 'assessment' with less of a follow up to reduce care role'.*

*'I am happy that all the responsibility for young carers is planned to be shared, but concerned on how responsive that will be and that young carers and their families will be passed around'.*

*'At the same time the young carers service funding has not been increased and we are struggling to deliver a comprehensive service on very low funding'.*

## Carers' Strategy and reviewing the legislation changes

A prospective new strategy for carers was announced in July 2015 by the Secretary of State for Health. Despite this announcement a strategy has yet to be published. In a response to the call for evidence from the Government on the strategy, Carers UK called for 'a review of the implementation of the Care Act 2014 and the Children and Families Act 2014 in relation to carers' assessments and support following assessments'.<sup>13</sup>

In 2015/6, the Carers Trust and The Children's Society delivered a one year Department for Education funded project to support the effective implementation of the duties required under the Care Act 2014 and the Children and Families Act 2014 with regard to young carers and their families. The project focused on six 'trailblazer' authorities including Barnardo's Liverpool young carers service. Amongst other changes, the Making a Step Change project identified a local memorandum of understanding between children's and adult services as key to joint working.<sup>14</sup>

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<sup>13</sup> Evidence for the Carers Strategy, Carers UK submission.

<sup>14</sup> Ecorys UK evaluation of the Making a step change: Putting it into practice project.

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Considering the variety of experiences from Barnardo's young carers services as a result of the legislation changes, a review needs to be conducted to ensure that support for young carers has not been adversely affected in some areas, and, if it has been, what can be done to resolve this. For this reason, we are calling for a review of the legislation to be included in the upcoming Government green paper relating to carers.

### **Recommendation 1**

Using the findings from the *Making a Step Change: Putting it into practice project*, any Government strategy or green paper on carers should include a review of the legislative changes in the Children and Families Act and the Care Act 2014 and the impact they have had on young carers and young carers' services.



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## 3. Identifying Young Carers

*'When dealing with adults, children are often invisible, when they should be the priority. Children should be asked questions about their life and their family if they are present at visits, this is the only way we can ensure that they are heard, through what they tell us they feel and need, not what others think they feel and need as the two can be completely different'. (Barnardo's young carer practitioner)*

In 2006, Barnardo's raised concerns that young carers were not being picked up by agencies and that statistics did not accurately reflect the number of young people with caring responsibilities in the UK. Barnardo's *Hidden Lives* report found that on average, young carers spent four years looking after a relative or parent before they were identified for support.<sup>15</sup> Some had even been caring for over ten years before they received any help at all. As well as this, nine out of ten teachers surveyed were concerned that some young carers remained 'unidentified and unsupported'.

### 3.1. Progress on identifying young carers

The situation has certainly changed legislatively in the last ten years. Barnardo's were part of the National Young Carers Coalition (NYCC) led by the Carers Trust which successfully lobbied to give responsibility for the identification of young carers to local authorities. The Children and Families Act 2014 and the Care Act 2014 both now state that 'all young carers under the age of 18 have a right to a needs assessment as a responsibility of the local authority, which must take 'reasonable steps' to identify young carers in their area who have support needs'. Our services agreed that this has resulted in an increased number of referrals to the services. **44% of practitioners cited an increase compared to 7% of practitioners that reported a fall in referrals.** However, they also told us that this has led to a certain ambiguity as to where the responsibility for identification and referrals lies within the local authority.

The Children's Commissioner's 2016 report *Young Carers – the support provided to Young Carers in England* requested referral data from all local authorities. The data gathered suggested that 'only a small proportion of young carers in England are identified and supported by their local authority'.<sup>16</sup> The report also suggests that although local authorities may be focussing on their statutory duties to undertake a needs assessment, it is at the detriment of actually providing concrete and specialist support to them. So even though the right to a needs assessment is in legislation and 97% of those assessed were deemed to be in need of support as many as 30% of those referred were not assessed. This equates to nearly 6,000 children.

### 3.2 Multi-Agency Identification

*'Agencies should come from the stand point that no child or young person should be put in a position where they are having to carry out inappropriate caring roles and if a young person is doing this looking at how they can reduce that role so that a child can have the same life chances as their peers.' (Barnardo's young carers practitioner)*

When it comes to identification, no agency can have sole responsibility as it is impossible to predict which frontline professional will be the first point of contact for these young people and families. GPs, teachers, mental health and drug and alcohol support services, adult social care, wider NHS services such as hospital personnel and children's social care could all be the agency that first identifies the family/child/young person. What needs to be consistent is that they are asking the right questions and the correct pathway is in place to ensure these families get the specialist help they need. As a Barnardo's practitioner highlighted, adult social care plays a crucial role: "a lot more work needs to be done with adult services who come into contact with the cared for person and should be asking the relevant questions." Even if the agency solely works with adults, it is imperative that they are thinking about the children and young people involved and the impact of the adult's situation on them.

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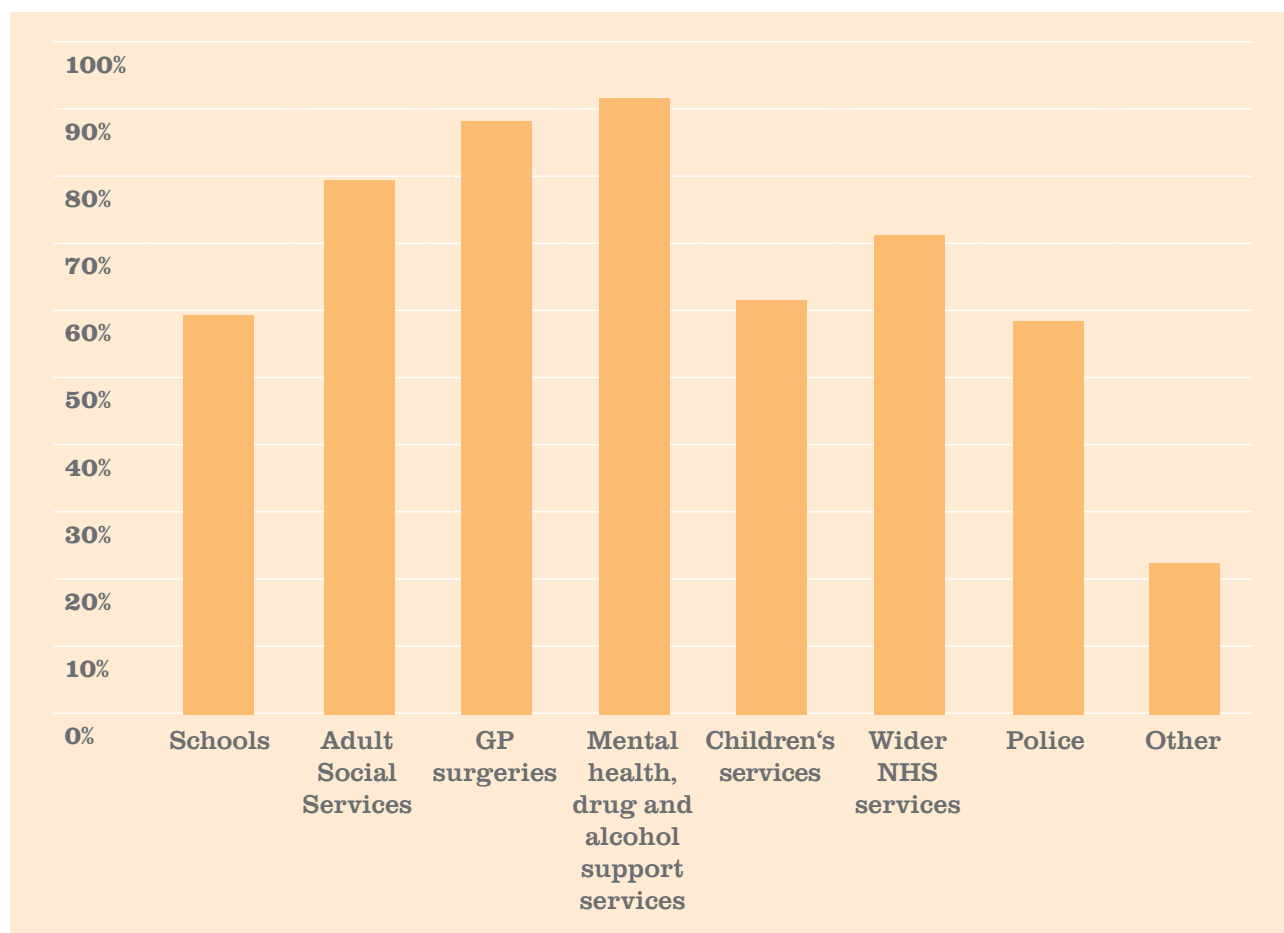
<sup>15</sup> Hidden Lives, Unidentified Young Carers in the UK – Barnardo's, 2006.

<sup>16</sup> Young Carers – The support provided to young carers in England, Office of the Children's Commissioner, December 2016.

All frontline staff should be trained to understand the issues young carers face, to spot the signs and to know what the processes are to ensure that these young people get the support they need. When adult

services are involved with the family, there should be no reason for young carers to go unnoticed because of a lack of knowledge or understanding from professionals.

**Table 3.2 – Which agencies do practitioners think need to do more to help and support young carers?**



As shown in the table above, 92.5% of practitioners said they thought that mental health and drug and alcohol support services needed to do more to identify and support young carers. These services will often be the first point of contact for patients who have disabilities, mental ill health and addiction issues. When these services are working with adults, are they asking vital questions about who supports them in the home and whether there are any children who will be impacted? As one practitioner told us

*'Adult services and drug/alcohol/mental health services are focused on the needs of the adult client and fail to recognise the caring role undertaken by children in the family and the impact on them.'*

Another practitioner said

*'I think agencies need to be more aware of what is happening within the family aside from what their job role covers. When dealing with adults, children are often invisible, when they should be the priority. Children should be asked questions about their life and their family if they are present at visits, this is the only way we can ensure that they are heard, through what they tell us they feel and need, not what others think they feel and need as the two can be completely different.'*

### **Recommendation 2**

Local authorities and agencies must ensure that all services who work with adults are also aware and trained on the impact the adult's condition/situation has on any young people and are asking the right questions to ensure the young person is identified to receive the help they need.

### **Recommendation 3**

Local authorities and other stakeholders should co-ordinate an awareness raising campaign undertaken within communities, pre-schools, leisure centres, churches, youth clubs, mosques and other religious places to raise the profile of young carers and the issues they face.

## **3.3 Identification in Health Services**

Barnardo's young carers practitioners cited GPs as a key service that could do more to identify and support young carers with 87% of our respondents naming them. Adult social care and wider NHS services were also highly cited. We know from talking to young carers in our services that many feel that the GPs and hospitals who were treating their family members had an opportunity to put more support into place therefore relieving the burden on the young person. In most cases this opportunity was not taken – one service said they only knew of two GP referrals in over five years and another service had never received a referral from a GP. Referrals from adult services are still limited yet it was stressed that GPs must come across and be made aware of more young carers through their day to day surgery consultations than many other more specialist agencies/services.

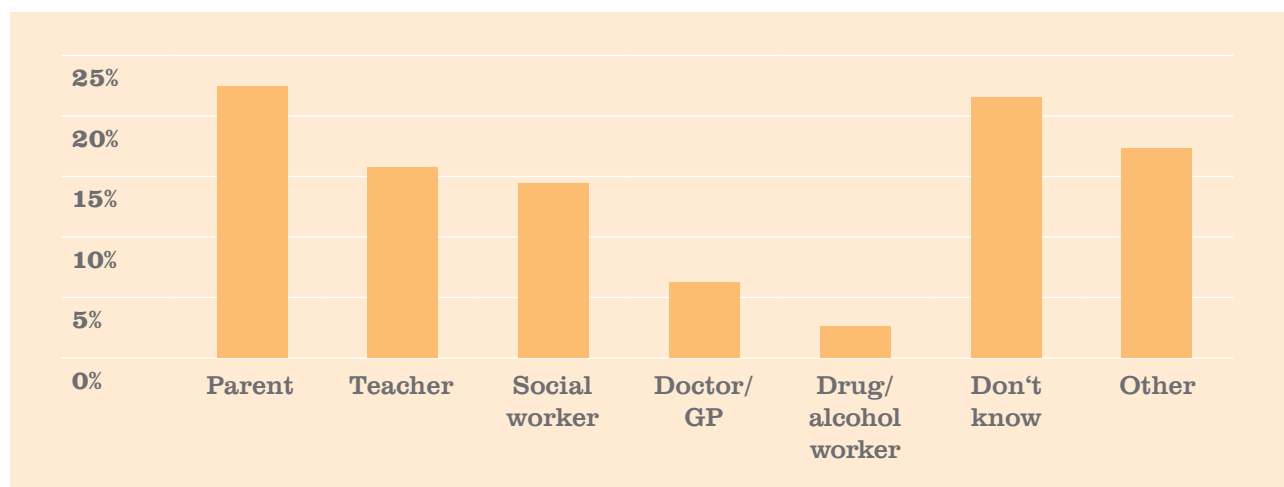
One practitioner told us that *'GP's could have a checklist of questions to ask about caring if they have patients with long term chronic illness, drug and alcohol issues or mental health issues that have children. This is the same issue for mental health and drug and alcohol teams as they may be the first point of identification. Agencies need to be aware of their responsibilities under the Care Act 2014 and to ensure that they know and use the local pathway for young carers and understand a 'no wrong door approach'.*

Another said hospital personnel need to be asking more questions when working with vulnerable adults or adults with chronic or long term illnesses. According to our young carers practitioners, these services are not ensuring young people are safeguarded and that young carers are being referred to their young carer service. The key questions are routinely not being asked and young people are slipping through the net. If the right questions were being asked, adult services should be able to put more in place to help the cared for person and therefore help reduce the impact of caring on the young people in the family. Many adults being discharged from hospitals are going back to households with only children to care for them with little if no support from professionals.

As the next page shows, whilst over 22% of young carers were referred by a parent and 15% said a social worker, only 5% told us that a GP had identified them. In a focus group in Newcastle, a young carer told us that despite repeated visits to a GP both for herself, her little brother and her mum, she was never referred to a young carers' service. The same young carer visited and cared for her mum and her new-born brother in hospital and she would divide her time between caring for both of them. She was very tired and stressed, constantly missed school but felt there was no other option. Upon discharge, there was no assessment from the hospital about what support was needed for either the mother or the new-born brother and the young person became the sole carer for both over the next few years leading to her leaving school and becoming increasingly isolated. It was only when a health visitor for her infant brother picked up the amount of caring she was doing that she was finally referred to Barnardo's.



**Table 5: Who identified you as a young carer and referred you to a service?**



In our survey of young carers, the overwhelming percentage of respondents indicated they were caring for a female parent. Therefore when doctors and other health service professionals are discharging female parents with care needs who have children under 18, it would be particularly helpful to ensure they check on the support needs for children who may be taking on a caring role.

The average hours worked by those young carers who had been referred by a doctor is 20 hours, so doctors are clearly identifying young carers who face a high burden of care.

It is also vital these recommendations for health care professionals are taken on across the full range of health services. Whilst the number of young carers who are caring for

someone with a physical disability is high (50%) the number caring for someone who suffers mental ill health is even higher (55%). Indeed 90% of respondents were caring for someone with a physical disability, a mental health issue or a long-term health issue therefore the role of health services in identifying them is crucial.

Adult social care, GPs, mental health and drug and alcohol services should be identifying young people who are taking on the caring role so that the emphasis is taken off young people identifying themselves. This would increase identification as young people are often reluctant to identify as they do not want to get their parents into trouble, so questions being posed to the parents will ensure the young person does not feel responsible for getting services involved.



#### **Recommendation 4**

Hospitals should ensure that when someone is discharged from their care, there is an opportunity for the question of who will support the adult at home to be asked. This should be recorded and shared with other agencies to ensure that young carers are being identified, supported and are not slipping through the net.

#### **Recommendation 5**

GPs should ensure that when they are seeing parents with long term illnesses, disabilities, mental health and drug/alcohol dependency issues, a thorough assessment is made of the children living within the household and that clear pathways are put into place to refer these young people to the relevant services when necessary.

#### **Recommendation 6**

Training on spotting the signs and asking the right questions should be provided for GPs, drug and alcohol support services and adult mental health services.

#### **Example of Good Practice Promoting family contact when a parent/family member is in hospital. Mersey Care NHS Foundation Trust and Barnardo's Family Rooms**

The Family Rooms initiative came about as a result of a ground breaking partnership dating back to 2001 between Barnardo's Keeping the Family in Mind (part of Barnardo's Action with Young Carers service in Liverpool) and Mersey Care to ensure young carers voices are listened to and acted upon by service providers and commissioners.

Family Rooms provide a safe, comfortable and homely environment for children, young people and their families when they visit a family member staying in the specialist mental health (including secure services), learning disability or substance misuse service. The rooms have all been designed with young carers and they meet the standard set by carers by using the Jelly Baby logo to illustrate the trust is thinking family.

The family room facilitates safer visiting and critically children, young people and families report visiting is less stressful. This is seen as an essential part of helping families stay in contact and this can have a positive impact on their recovery.

### 3.4 Identification in Schools

There is strong support for educational institutions to play a leading role in the identification of young carers. Ofsted specifically mention young carers in their Common Inspection Framework *‘Young carers are a vulnerable and disadvantaged group, as a result, these pupils will have specific needs to which the school must respond’*.<sup>17</sup> In our survey of young carers supported by Barnardo’s, teachers came second only to parents for who had identified the young carer for referral. The average age that young carers started caring was lower for those referred by teachers (7.8) than that for young carers referred by doctors (12.8). This indicates that primary school teachers play a crucial part in identifying young carers who start caring early, whereas doctors have an important role in identifying young carers who become carers as adolescents.

In the survey of Barnardo’s practitioners, there was also overwhelming support for schools being enabled to identify young carers. Over 95% cited schools as key in helping with the identification of young carers as well as providing a means for engagement with their families. A clear majority of respondents cited a need for schools to support referrals (84%) and raise awareness (68%).

In October 2017 Barnardo’s conducted a YouGov survey of more than 800 teachers to better understand the current provision for young carers in schools and the opportunities for improvement.

The YouGov survey revealed that almost three quarters of teachers and 81% of head / deputy head teachers felt that schools had responsibility to refer young carers, but that **45% of secondary school teachers said they did not feel confident they would recognise a young carer and over a third (36%) said they did not feel confident about how to refer any young carers they did identify to external support services.**

Three years on from the 2014 Act, 34% of all teaching professionals and 48% of head / deputy head teachers think there are children at the school who are not sufficiently supported.

Worryingly given the scale of the problem identified, only 26% of educators surveyed said

there was a mechanism for identifying young carers at their schools and only 19% said their school provided training on young carers to teachers.

One strong feature of the respondents from the young carers supported by Barnardo’s is the age they started providing care. 12% of respondents had started caring by the age of five and two thirds provided care whilst they were still in primary school. This makes it particularly important for primary schools to identify young carers and transition that information into secondary schools. Yet the YouGov poll shows that only 28% of primary school teachers have supported young carers compared to over 50% in secondary schools suggesting this may not be happening.

Most starkly with at least 1 in 12 secondary school students estimated to be young carers, it is clear that the majority of schools need to put in place improved provision to ensure that the impact of the caring is minimised as much as possible.

#### Recommendation 7

All primary school, secondary school and college application forms must have a tick box to give parents the opportunity to inform the institution that their child is a young carer in advance of them starting. Transition arrangements should also be put into place between schools to ensure that support is consistent.

#### Recommendation 8

Schools must ensure that there is a designated member of staff responsible for young carers and that their name is published on their website.

<sup>17</sup> Ofsted Common Inspection Framework 2015.

### **Recommendation 9**

There should be mandatory training for all teachers to spot the signs of young carers provided both on teacher training courses and within schools.

### **Recommendation 10**

All schools should have a young carers policy which is reviewed regularly.

### **Recommendation 11**

Partnerships between schools and young carer services should be established in order to ensure that communication and support is improved for young carers.

### **Recommendation 12**

More schools should sign up and utilise the Carers' Trust and the Children's Society's Young Carers in Schools programme, anti-bullying training package and awards scheme.

### **Example of Good Practice Young Carers in Schools**

There are many schools and teachers who are working very hard to support young carers in their schools. The Carers Trust and the Children's Society have been leading the way in their work with schools in recent years and have developed a free programme for all schools in England on identifying and supporting young carers and guidance on using the pupil premium to support young carers. As part of this programme, they also run the Young Carers in Schools Award, which enables schools to gain recognition for effective practice. Many of our practitioners cited this programme and the resources it provides as extremely beneficial to schools and reported that they do encounter schools with good policies in place to support young carers but it continues to be inconsistent. More schools need to join this programme and utilise the resources it offers. Closer partnerships between schools and the local young carers' services are vital in order for support to be both appropriate and consistent.

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### 3.5 Challenges in Identification

It is important to remember that difficulties in identification are not only due to ineffective processes across the relevant agencies. The Barnardo's 2006 report referred to hidden carers and a culture of secrecy being adopted by families and young carers themselves. This is not always deliberate. The census figures rely on self-identification and many families do not recognise what these young people are doing within the family as 'caring'. However, sometimes the secrecy is deliberate. There are numerous reasons for this secrecy either from the families of the young people themselves but primarily it seems to stem from a fear of the consequences from the authorities if it is declared. Over 90% of our young carer practitioners surveyed said that they believed there were young people who did not want to be identified.

When responding about the reasons for this, words such as stigma, shame, fear, embarrassment and lack of understanding were cited repeatedly. One practitioner said *'Fear of being removed from family - not enough is done to promote positive images and case studies of positive parental role models as disabled parents'*. Another told us that the fear often came from young people themselves who *'are concerned that their peers will see them differently'*. The parent or sibling's illness could often also be the cause *'Hidden harm cases such as substance misuse there is a strong element of secrecy due to criminality. In terms of mental health, there is a strong embarrassment factor due to lack of understanding and bullying'*. As mentioned earlier, cultural expectations are also a significant factor. Young carers are more than one and a half more times as likely to be from Black, Asian or minority ethnic communities and twice as likely to not speak English as a first language.<sup>18</sup> Practitioners from our Newcastle service in Newcastle, Barnardo's practitioners commented how they have had no referrals from a particular ethnic minority group and were pro-actively seeking ways to engage with this community to ensure its members were aware of the support available to them. Our young carers service in Leicester has successfully worked hard to engage families from ethnic minority communities, even employing a specific minority support worker. The Children's Society reaches out

to such communities through their specific 'Include' programme which includes an 'Engage Toolkit' for practitioners.

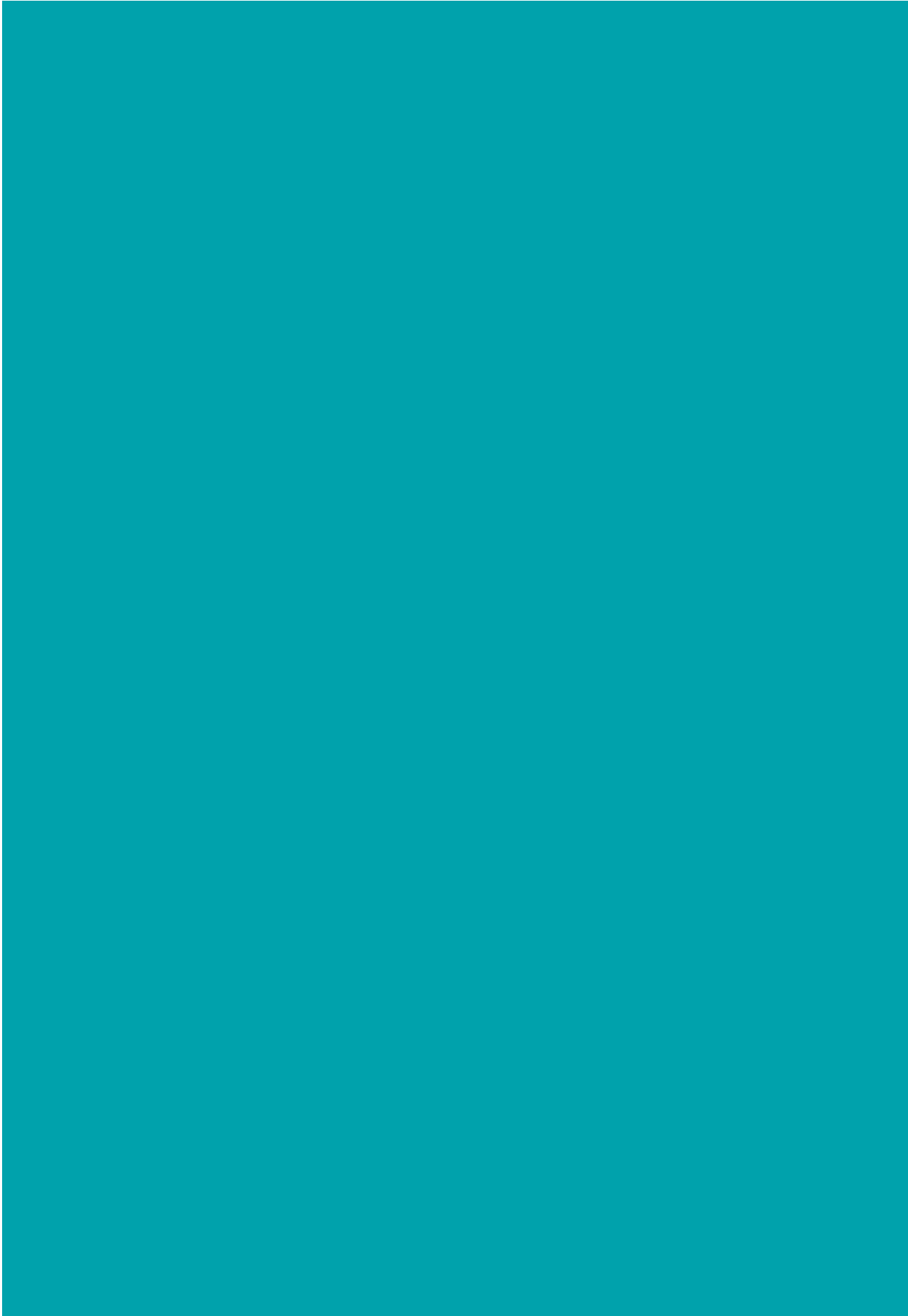
The YouGov survey of over 800 teachers found that 50% of educators feel young carers hide their situation from teachers. Three in every four teachers (76%) feel young carers will hide their situation from their classmates and 57% of teachers felt young carers will hide their situation from figures of authority such as the police, social workers and health care professionals. More needs to be done to reduce the stigma of caring and increase the lines of communication open to young people within schools to give them more opportunities to open up to staff.

#### Recommendation 13

As a particularly vulnerable and often overlooked group, schools, local authorities, health services and young carer services need to work to identify, engage and provide specialist support for BAME young carers in order to break down barriers and reduce the stigma and fear of agency involvement within these communities. Services need to be accessible and visible and work to overcome any language and cultural barriers that may lead to BAME families not seeking support.

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<sup>18</sup> The Children's Society, Longitudinal Study of Young People (2013).



## 4. Support for young carers

*‘Support has become more targeted and we do less in the way of fun activities/respite. We have more referrals and less funding’  
(Barnardo’s young carer practitioner)*

Whilst identification must remain an immediate priority for all authorities, it is also vital that appropriate support is provided to minimise the long-term impact on young carers. This section looks at the journey post identification and assesses the support provided in schools for young carers and also looks at direct services for young carers, mental health support and the conflicting emotions young carers face.

Too often, being identified as a young carer does not change much for the young person who continues to trade off their future in order to help their loved ones. Institutions working with young people including schools, health, and social services need to ensure they are looking out for young carers and providing them with the support they need.

Unfortunately, support for young carers in many parts of the country remains insufficient, and in some cases the situation is getting worse. In the survey of Barnardo’s practitioners, 75% of practitioners highlighted how reduced young carer support services are making it more difficult to overcome the negative impact on caring has this vulnerable group of young people.

The hard won 2014 legislation had a positive impact on identification but unfortunately the funding for young carer support has not kept pace with the increased referrals and far too many young carers are still sacrificing their futures even after authorities are aware of their situation.

In assessing the impact of the legislation from 2014, practitioners working with young carers across the UK have welcomed the increased reporting and referrals but are also clear that the hoped for increase in young carer support has not been realised. Practitioners highlighted a number of key challenges three years on from the legislation change.

- “Some local authorities have taken young carer support in-house and are now just providing ‘assessment’ with less follow up.”
- “Reduced funding means that being able to access support for young carers and the cared-for person has become more difficult and there are increased waiting lists everywhere.”
- “As a result of the increase in referrals, it can occasionally feel that we are having to focus on completing assessments more quickly.”
- “We do not have enough time before closing a case to follow up referrals to other agencies – having to rely on them being actioned.”
- “The early help are quick to pull out stating that we and maybe other services are supporting the family...it can feel like we end up doing a lot of the job that we would be expecting them to do”.
- “By making it ‘everybody’s business’ it has almost become nobody’s business”.

### Recommendation 14

Local authority commissioners need to reassess funding structures to ensure that the focus and funding is not just on the identification and assessment of young carers but also on sustainable and worthwhile support.

### 4.1 Support Pathways for young carers

Improved training and understanding about young carers from professionals working with adults is just the start of the journey to support. The communication, processes and pathways that are put in place following identification are just as crucial to ensure consistency and effective support. These

pathways appear to vary greatly from one local authority to another but where strong partnerships between young carer services, adult and children's services are in place, the pathways are more effective and are working better for young people. As well as this, it is imperative that referring young carers on should not be the end of the case for the identifying agency but more the beginning of an outcome focussed partnership between agencies involved with the family.

A designated person within adult social care with knowledge and responsibility for young carers would provide a consistent point of call for all agencies and families in order to co-ordinate the pathway to support.

Our Liverpool young carers' service has a member of staff with a dedicated role working alongside adult services (including mental health services) to enhance their understanding of issues for young carers. This is something that could be replicated in other local authorities to ensure that all professionals regardless of whether they are supporting the adult or child are looking at the needs of the family as a whole. Some examples from our services where this commitment is needed is when meals are provided for adults under social care, their children should also be provided with meals and when parents are not well enough to take children to school, support workers should provide transport.

### **Recommendation 15**

Local authorities and agencies must have clear embedded pathways for young carer support and improve cross partnership working between all children and adult services.

### **Recommendation 16**

Local authorities should appoint a designated officer within adult social care with responsibility for young carers, transition assessments and support to ensure that there is a consistent point of contact for families and other agencies.





### **Recommendation 17**

All local authorities and agencies need to adopt an outcome focussed follow-up approach rather than referring young carers on and then closing the case.

### **Recommendation 18**

Agencies must work together to provide joint, online support for young carers recognising this is a preferred and accessible method for many young people and how they would prefer to receive support.

### **Example of Good Practice Liverpool's Approach to Young Carer Assessments**

Liverpool City Council has devolved its statutory function to offer young carers assessments to its commissioned provider Barnardo's Action with Young Carers. The process of assessment has been co-produced by the Council, Barnardo's and critically young carers who have had direct experience of assessments. The young carers' pathway sits in the heart of Liverpool's Early Help Framework. This provides a robust, integrated, whole family framework to bring adults and children's services together, creating resourceful and resilient families. It has been

highlighted as a good example of taking a whole family approach to the identification, assessment and support of young carers. (*Barriers and solutions to implementing the new duties in the Care Act 2014 and the Children and Families Act 2014 – The Children's Society*)

Aligned to this, Mersey Care NHS Foundation Trust in partnership with Barnardo's has reviewed its policy and procedure for identification of young carers and assessment process policy. The policy has now been developed to ensure all Mersey Care NHS Foundation Trust staff understand young carers' rights to a young carer's assessment and support under both the Care Act 2014 and Children and Families Act 2014. It is designed to ensure that young carers are identified and offered a separate assessment of their own needs if it is their choice to do so and that those assessments are carried out in accordance with legal provisions and local contractual agreements.

## **4.2 Young carers in Education**

Given young carers spend the majority of time within a school setting it is essential they are at the forefront of providing support for young carers. Indeed, over half of the young carers supported by Barnardo's think that schools should do more for young carers and three quarters of these young carers think more awareness is needed in schools. Over a third of the young carers indicated that as far as they know their schools have **never** given extra support to young carers.

In October 2017, Barnardo's partnered with YouGov to commission a survey of young carers in UK schools with over 800 educators participating.

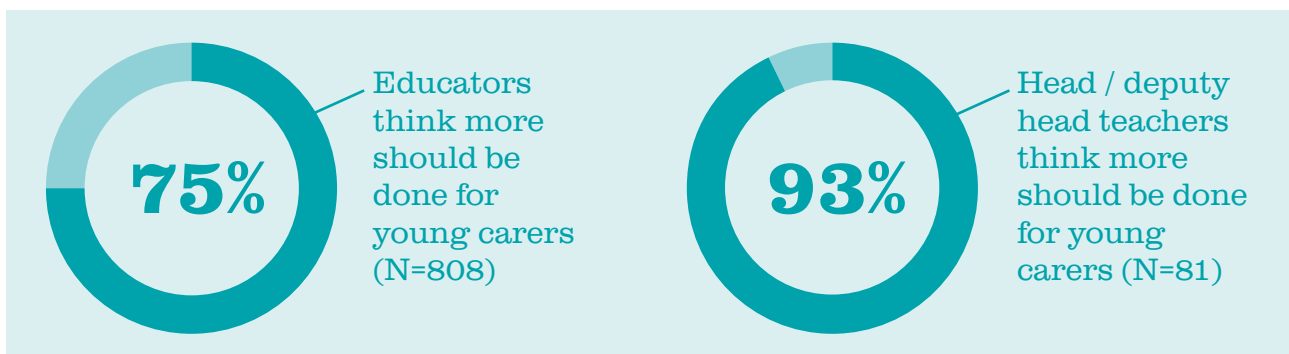
The results are striking and provide stark evidence of the paucity of support for young carers in UK schools today.

**One in three teachers (34%) admitted they don't think their school has any particular way to support young carers.**

The vast majority of teachers feel that far more needs to be done for young carers in schools. Overall **75% of educators and a staggering 81% of head / deputy head teachers think more should be done within UK schools to support young carers.**

Only 13% of teachers think the right amount is being done and **less than 1% of teachers thought young carers were getting too much support.**

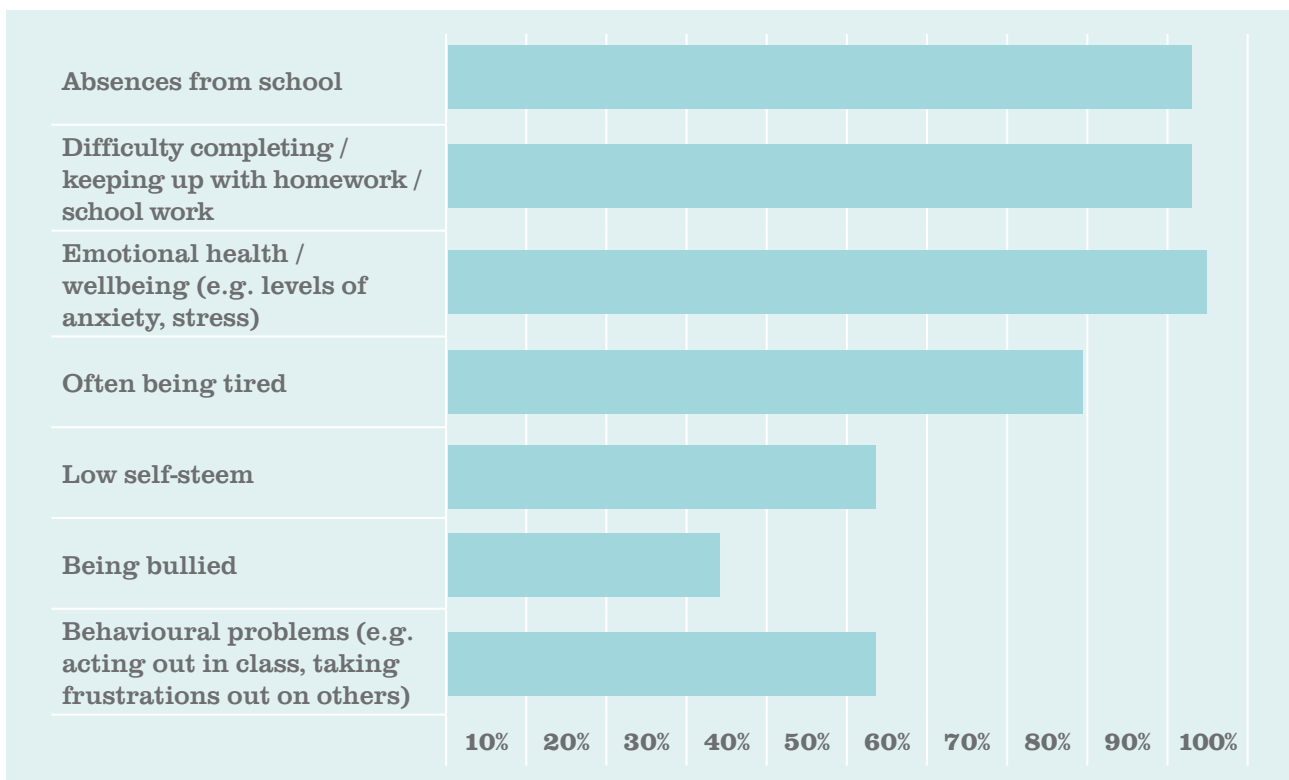
**Fig 1.1 The percentage of respondents who think more should be done within schools to support young carers following:**



**Impact on pupils who are young carers**

The data on the impact on pupils who are young carers was even more overwhelming

**Fig 1.2 The percentage of teachers identifying challenges faced by young carers (N=808)**



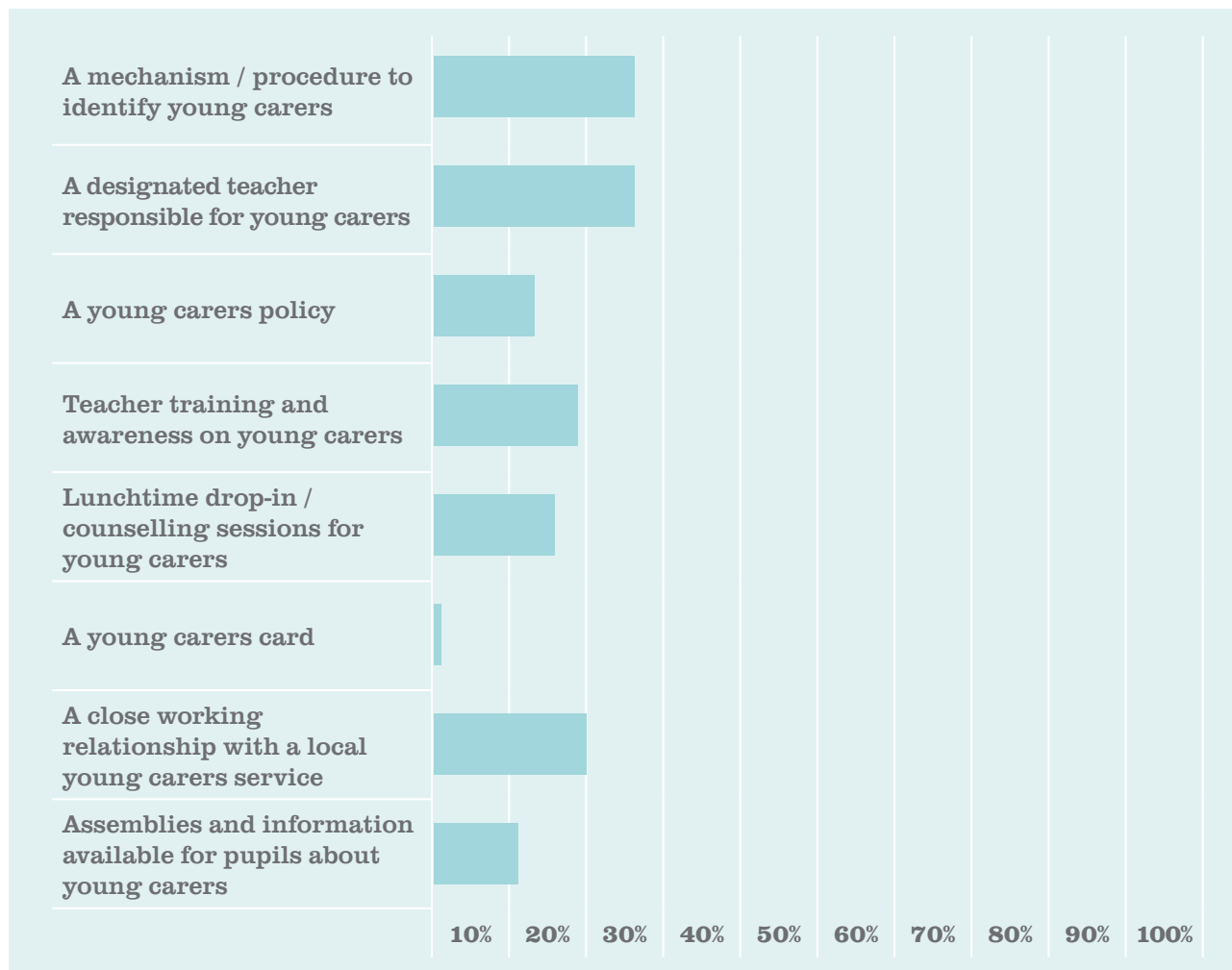
More than **nine in ten teaching professionals felt that caring responsibilities could mean that young carers were late or absent from school** and that it is difficult for young carers to keep up with work. 98% of head / deputy head teachers said they thought being a young carer could impact on children’s emotional health and wellbeing.

### Support Services for young carers in UK schools

The YouGov poll also showed a low amount of current support services for young carers across UK schools and **over one third of teaching professionals (34%) reported there were young carers at their schools who were not sufficiently supported.**

When assessing the support to young carers in schools, 40% of educators reported they had personally supported young carers with a significant difference between teachers (31%) and head / deputy head teachers (65%).

**Fig 1.3 The percentage of teachers identifying types of support for young carers in their school (N=808)**



This significant difference between teachers and senior staff is also seen in assessing the support for young carers in schools. **41% of head / deputy head teachers think there is a person identified in their school for young carers but this number falls to less than one in four for teachers** (23% and 26% overall). Similarly, 30% of

head / deputy head teachers said young carers are covered on teacher training days whilst less than one in five teachers said the same (17% and 19% overall). This indicates that approaches to young carers in school not only need significant improvement but they also need to better promote and communicate to all staff.

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Across all schools, the lowest areas of support provided were having a young carer policy and young carer identification cards support across all staff at their school. **Less than one in eight teachers said there was a young carers policy** (12%) and just 1% said that their school had ID cards so young carers could quickly explain their circumstances to teachers by showing the card.

The YouGov results also showed significantly different levels of provision between primary and secondary schools. For example, those working with young ages were less likely to have specific support for young carers with **40% of teachers working in Key Stage 1 (KS1) and 35% in Key Stage 2 (KS2) reporting that they didn't think their school had any specific support for young carers almost twice the rates for Key Stage 3 & 4 (19% & 18%)**. This is particularly troubling as the survey of Barnardo's young carers indicated that most young carers start caring when they are in KS1 & KS2 meaning young carer policies in primary schools are important.

## Comparing the data with Young Carer and Practitioner surveys

The data from the YouGov survey also correlated strongly with the findings from our research with young carers and practitioners.

Amongst the young carers supported by Barnardo's, the number who said that being a young carer meant they can't do their school work as well as they liked, increased from primary school to secondary school (25% to 40%) unsurprisingly as the burden of work at home and at school grows. For secondary school girls the percentage rises to 57%.

Every single Barnardo's young carer practitioner surveyed felt young carers face difficulties balancing their work and caring responsibilities. 75% felt financial pressures mean young carers often have to choose earning over further education, whilst 95%<sup>19</sup> felt that young caring responsibilities mean young carers will not necessarily be able to go to the further/higher education institution. Even where they do, it was felt many do not enrol for the course they might ideally want to if it was

likely to affect their caring responsibilities. 63% of Barnardo's practitioners felt that schools can help by providing counselling to young carers. Exams are a particularly difficult time. Over half of young carers identify exam time as the most difficult period, and this number rises to 57% for girls and 70% for those young carers who are 14 and over. This was supported by the results of the Barnardo's practitioner survey, where over 90% of practitioners felt that exam time was more difficult for the young carers they worked with.

It is already proven that young carers' educational attainment is significantly lower than their peers. 27% of young carers aged 11-16 experience educational difficulties or miss school because of their caring responsibilities, rising to 40% for young carers with parental mental ill health/substance misuse. They have significantly lower educational attainment at GCSE level – the difference between nine Bs and nine Cs.<sup>20</sup>

Being a young carer also has a significant impact on education beyond school and the longer term. Many young carers struggle to achieve qualifications they are capable of and young adult carers aged between 16 and 18 years are twice as likely as their peers to not be in education, employment or training (NEET).<sup>21</sup> Young carers are also more likely to earn less in their 20s than their peers.<sup>22</sup>

A stark finding from the Barnardo's young carers survey, is that for those young carers who are above school age, 50% of them indicated being a young carer had prevented them from further study or led to them dropping out. 25% indicated that being a young carer had prevented them from going to university. 10% said that it led to them dropping out of secondary school and a further 15% said that it led to them dropping out of their college or university. This subset of the data is relatively small and would benefit from further study but it shows how heavy a price a young carer pays.

Overall it is clear provision in schools and colleges needs to significantly increase if the crisis facing young carers is to be properly tackled. Barnardo's is proposing a series of recommendations for schools and colleges based on the suggestions from teachers, head

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19 (Carers Trust 2013) nb – albeit recognising that the GCSE gradings system has been overhauled since this research was published.

20 (The Children's Society, 2013) - Note the addition to this footnote to reflect the GCSE grading system changing this year.

21 (The Children's Society, 2013).

22 (Census data 2011).

teachers, young care practitioners and young carers themselves.

## Quotes from young carers about school, college and university

*"I dropped out of my first year in university due to caring for my mum as she become very ill and needed full time care"*

*"Being a young carer stopped me from choosing whether to move away for university or not."*

*"I couldn't handle school, my caring and my own mental health issues."*

*"I missed the last year of school"*

*"If I end up moving anywhere, my mum would be alone and she needs constant support"*

*"Being a young carer, home life was too stressful and college wasn't understanding and I wasn't 100% focused on assessments at college."*

*"I had to drop out to care for my mum."*

*"I didn't want to move away for university so stayed closer to home and didn't do the course I would of loved to have done."*

*"My mum didn't want me to move away from home or be in full time education."*

### Recommendation 19

There should be more support in schools and a better understanding by school staff of the impact caring has on a young person.

For example by:

- Allowing young carers extra time with homework & provision to sit exams at home
- Allowing young carers to use their mobile phone when needed
- Being more understanding if young carers are late or miss school
- Providing young carers with a card that can be shown to teachers in order to identify them quickly

### Recommendation 20

Schools must raise awareness about young carers and their situation to other children to reduce stigma and shame through assemblies, posters, classroom activities, speakers and PSHE lessons.

### Recommendation 21

Schools should improve outreach work and get to know the families involved and their issues better in order to fully support the young carer.

### Recommendation 22

Schools must look at providing peer support within the school day to give young carers the opportunity to meet up with each other.

### Recommendation 23

Career's advisors within schools and externally need to be trained to be aware of the challenges young carers face when making decisions about their futures post-secondary school and must be able to offer relevant advice and support.

### **Recommendation 24**

More partnerships between young carer services and higher education institutions should be established as they are proving to be effective at breaking down the barriers many young carers face at universities. Further engagement should be sought with Universities UK and other umbrella organisations to extend this effective working across the country.

### **Recommendation 25**

Employment, training and skills providers and advisors should be fully trained in the issues young carers face when seeking employment in order to ensure that they are properly advised on their options and know of the opportunities available to them.

### **Example of Good Practice Leicester and Leicestershire Young Adult Carers Network**

The Leicester and Leicestershire Young Adult Carers Network was established in 2013. It brings together a range of learning providers, services and agencies from across the city and county to improve the transitions within education and from education to work for young people with caring responsibilities. The Network is convened and chaired by Barnardo's CareFree Young

Carers' Service. Established in 1996, CareFree provides a range of support services to over 500 young and young adult carers aged 19 or under in Leicester and Leicestershire every year. The service also works with a range of organisations to improve the identification of young (adult) carers by raising awareness of this group, the support they need and the impact this role can have for children as young as five years old.

The Network has regular attendance at its meetings from all three local universities; a range of sixth forms and colleges, both local authorities' adult and children's services, and both careers advice services. In addition, they engage specialist support as and when required, such as representatives from the Department of Work and Pensions, Voluntary Action Leicestershire, the Leicestershire Local Enterprise Partnership (LLEP), and specialist young adult carer workers from other counties.

All of the organisations involved in the Network have improved their support for young adult carers internally and externally. Many of the universities, sixth forms and colleges now have policies and leads for young adult carers in place, and there are now named young or young adult carer champions in almost all of Leicestershire's secondary schools and colleges.

## Example of Good Practice

### Working with Higher and Further Education to support Young Adult Carers

Barnardo's Action with Young Carers Liverpool is commissioned by Liverpool City Council and jointly funded with Liverpool Clinical Commissioning Group to support young adult carers up to the age of 25. Barnardo's facilitates a steering group that has membership from a network of local higher and further education institutions. This has provided a forum to support collaborative working with further and higher education colleagues in Liverpool primarily across Merseyside. The coordinated approach has allowed the service to develop new relationships with the different institutions and further develop existing ones. Allowing the service to continue its work in supporting young adult carers, to both aspire to accessing higher and further education opportunities, and, to get the right package of support from their institution, so they can succeed and enjoy university life as much as do their peers. This support is essential in overcoming the very difficult circumstances these young people face and will greatly help them acquire extremely valuable skills and to reach their full potential.

## 4.3 Young Carer Services

In addition to support at school (4.1), there remains a need for specialist young carer services including funded peer support and respite.

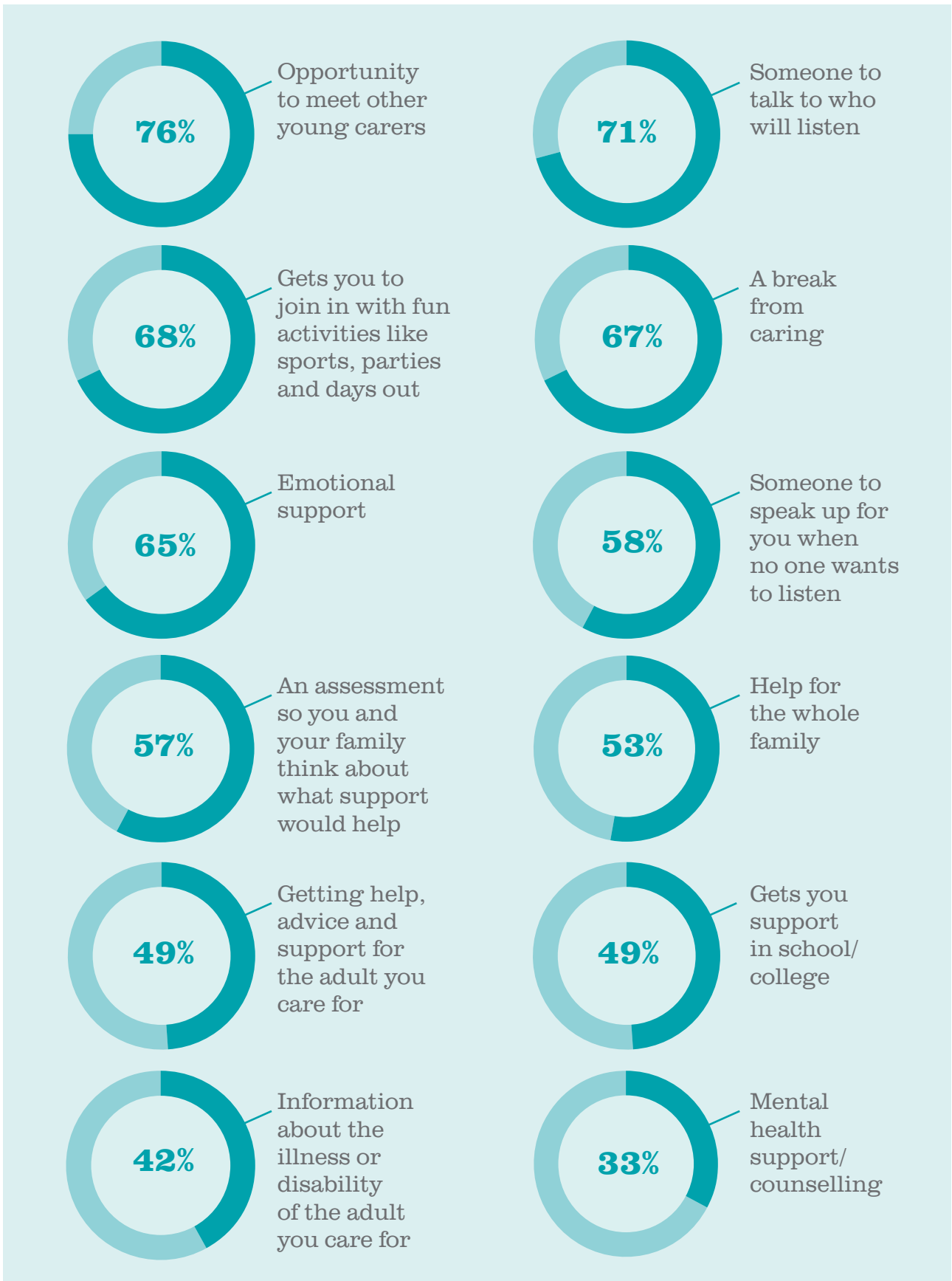
Young carers value this support. Peer support allows young carers to socialise and discuss issues in a safe space with people having similar experiences so they do not feel so isolated. Providing 1:1 support is also vital to understand and support them on difficult issues.

As a Barnardo's practitioner highlighted: *"almost all young carers and families need respite/break, time away from a situation to freshen the mental health well-being. Therapy – whether counselling or six to eight weeks interventions – works!"*

It is also important that all those working with young carers listen to them and give them the respect they deserve. Over the years, young carers have told us that a long-term service where they are able to build strong relationships on a consistent basis with professionals that don't regularly change is important. This means that they are more likely to drop in and out of accessing services when they need more or less support. Young carers tell us that where they feel that support workers have "invested" time and energy in them it makes them more motivated to achieve and fulfil their potential.

The survey of Barnardo's young carers also highlighted the impact that young carer services have had on their lives. 'Opportunities to meet with fellow young carers' and 'respite' figured in the top responses, highlighting all the more the damaging nature of the cuts to such services which we heard from practitioners. Local authorities have had to make tough spending decisions in order to meet their new duties around identification and assessment of young carers. However, it seems that they have seemingly often overlooked the impact that the increase in referrals has had on the amount of support they are able to provide.

**Fig. 1.7 Table of the most popular answers from Barnardo's young carers about how young carer support has helped them.**





*'It feels special even when it feels kind of horrible'.  
(young carer talking about her caring role, Preston)*

It is also important to remember that many young carers are extremely proud to care for their families and, despite the negative impact it can have on them and their outcomes, they are fiercely protective of their role. 63% said they were proud and happy to help their families with caregiving. A 20 year-old female young carer in Preston told the focus group that she enjoyed caring and she was "happy that her mum was happy" and it made her more "confident and caring with other people". However, the same girl also told us that in Year 8 she got referred to a service because she had stopped eating and talking.

Often it is the support from the young carers' service that ensures they feel more positive about their role. The service works to not only support the young carer but to advocate for more support for the family and will try to protect the young person from 'excess' caring or caring levels that will significantly reduce their life chances.

A number of young carers in our focus groups cited their experiences of caring as a major factor in helping them decide what sort of job

they wanted to do. They also discussed how caring matured them to a level beyond their peers and gave them a sense of responsibility that other young people had not experienced. One young carer in Newcastle told the group that she is very "organised – and I know how to do things other kids wouldn't know how to do".

The majority of young carers supported by Barnardo's indicated both positive and negative feelings associated with caring, for example over 60% of those who said caring made them feel 'anxious or worried' also said they were 'happy and proud to support their family' and 50% who said they 'couldn't cope' with being a young carer also said it made them 'happy and proud'.

These dual feelings help to explain why young carers don't always seek the support they need as they are willing to sacrifice their wellbeing and their future to help the ones they love. Young carers deserve our help and they are still being ignored by too many of those services that have a duty to support them.

Barnardo's young carers had the opportunity to tell us why the support they received from their young carers' services had made such a difference to their lives. Looking at the comments is a stark reminder of those young carers who are alone and unsupported. Some of the comments are in the table below.

*"The service has given me many unique opportunities."*

*"You are really helpful and you helped me understand what I need to know and helped me feel happier about everything."*

*"My project worker got me a place on the National Citizen Service, a sailing expedition and a weekly gym group."*

*"Made me feel more confident."*

*"Allowed me to be a kid."*

*"Helped me meet other young carers during group work."*

*"I feel very supported since coming to the service."*

*"My life wouldn't be the same without Barnardo's."*

*"Barnardo's helped make me the person I am today, they helped me find my voice."*

*"I have had lots of support in primary school because of Barnardo's."*

*They stick up for me when there is a different side of the story."*

*"They are very supportive and stick up for my mum and dad in meetings. They are very nice people."*

*"Made everything so much better!"*

*"Someone to talk to, group work, young carers' council, activities."*

*"With more support I feel a lot more confident."*

*"Support from young carers has been great, has made me feel like I'm someone."*

The young carer services commissioned by local authorities to give assessments and support, found that their funding focussed more on assessment and less on support which meant the support services were not always being statutorily funded. 21% of Barnardo's practitioners felt that there had been a decrease in the amount of support provided and 23% felt there had been a focus on assessments over support.

There is also an issue for the youngest carers. The Children's Society noted in their report *There's nobody is there? – No-one who can actually help* that between the two censuses, the age group that had increased the most relative to growth of other age groups was the youngest group – five to nine year olds.<sup>23</sup> Our survey also saw a high number of young carers begin their caring roles under the age of nine. Not only is it shocking that children of this age are care givers within their families but there is less structured support available for this age group.

100% of all our service practitioners had received referrals for this age group. A few are unable to offer services and commented that there was no local organisation working with this age group to refer them on to. Some said support for this age group came from community based organisations such as children's centres and Brownies. Many cited school as the crucial place for these young people to receive support.

### **Recommendation 26**

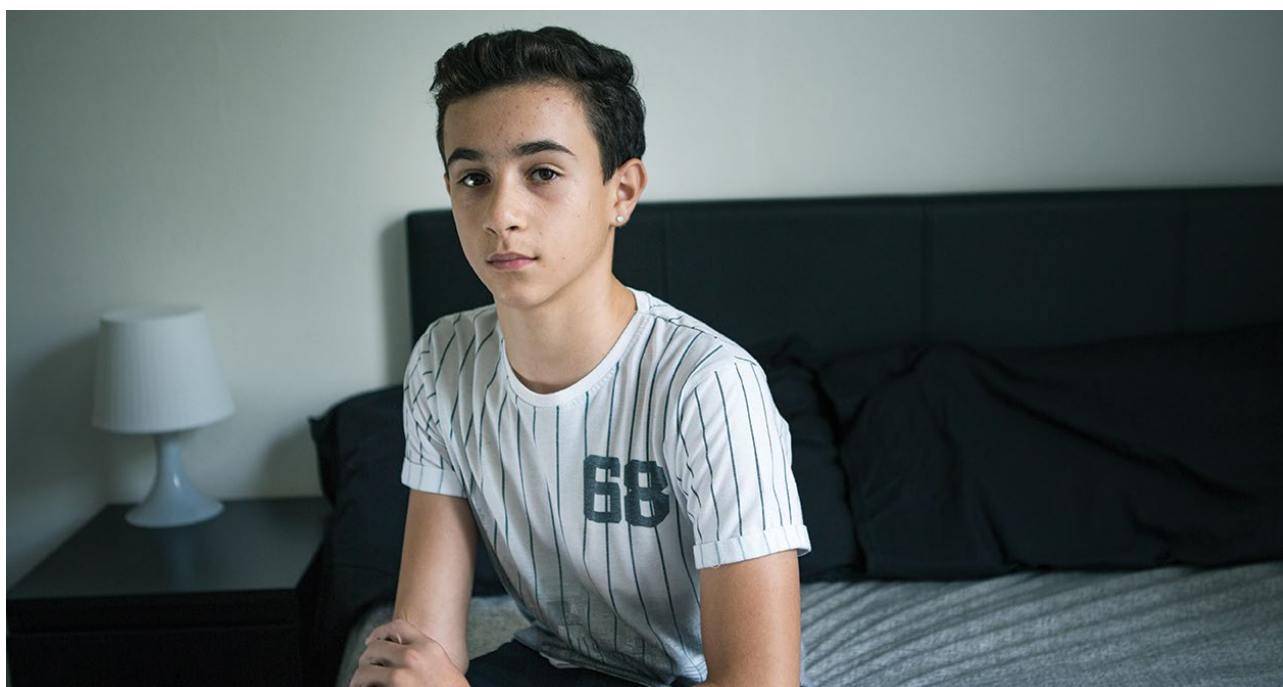
Local authority commissioners should look to create more Young Carer Councils as they are an excellent way to bring young carers together and help them feel empowered.

### **Recommendation 27**

Peer support and respite is vital when supporting young carers and where possible local authorities should make this available to young carers.

### **Recommendation 28**

Local authority funding should be made available to provide specific and appropriate support for young carers under the age of nine.



<sup>23</sup> *There's nobody is there? – No-one who can actually help*, The Children's Society, 2016.

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## 4.4 Emotional & Mental Health Support

*‘As well as the practical and physical task of caring, services need to recognise the impact of parental illness and substance misuse on the children’  
(young carer practitioner)*

It is clear from previous studies and the data in the YouGov survey that young carers are more likely than their peers to be bullied, miss school and have mental health issues. In their recent report, *Invisible and in distress: prioritising the mental health of England’s young carers*, the Carers Trust focused on the responsibility the NHS and Government have to improve access to support services. Schools as the day-to-day custodians also have a significant role to play.

In 2006, our *Hidden Lives* report stated that “40% of former young carers said their mental health had been directly affected. Emotional traumas, depression, stress and low self-esteem were not uncommon. Around 50 % had felt counselling was necessary because the stress of their caring years had left unresolved needs”.<sup>24</sup> This specific data was gathered 18 years ago yet it appears from our own surveys and focus groups that very little has changed.

In the 2016 Children’s Commissioner Report on young carers, when asked to select the most important types of service, a focus group of young carers chose the following as their top three:

- Someone to talk to
- Emergency/crisis plan
- Mental Health Support<sup>25</sup>

It is important to remember that adolescence is a challenging time for many young people. Debate is currently raging on the imbalance between a focus on emotional health support and educational attainment within schools. Children & Young People Now reported that mental health experts told the Joint Health and Education Select Committee that schools in England should only be rated ‘outstanding’ by Ofsted if they can prove they are committed to tackling mental health problems and improving the emotional wellbeing of pupils.

The Joint Health and Education Select committee conducted an inquiry into the role of education in children and young people’s mental health which is looking at the role of schools and colleges in promoting emotional wellbeing and preventing mental health problems. Earlier this year, Barnardo’s submitted a consultation response where we asked the committee to give special consideration to children and young people who are particularly at risk of developing emotional and mental health problems. Our response included a transcript of an interview with two young carers from Barnardo’s Young Carers Service in Redbridge who discuss the challenges they face in getting help at school with their emotional health and wellbeing.<sup>26</sup>

Young carers have challenges and worries above and beyond the typical young person. Most young people could not imagine having to feed and bathe their siblings or administer medicine to their mother. Above and beyond homework, exams and relationships, young carers often take the weight of their family’s stresses and strains on their shoulders with very little support. We asked our practitioners who work day in and day out with this group of young people what sort of issues they faced day-to-day.

**100% of those surveyed told us that some of the young carers they worked with had suffered from anxiety with nearly 15% saying this affected all of the young carers they supported.** Similarly, 100% of the practitioners had worked with young carers who had depression, isolation and feelings of anger and most felt the majority of young carers have those issues. All the practitioners had experience of working with children and young people who had self-harmed.

One practitioner wrote “*Sometimes professionals just do not realise the emotional impact (being a carer) it has on a child*”. Another said that “*as well as the practical and physical task of caring, services need to recognise the impact of parental illness/substance misuse on the children*”.

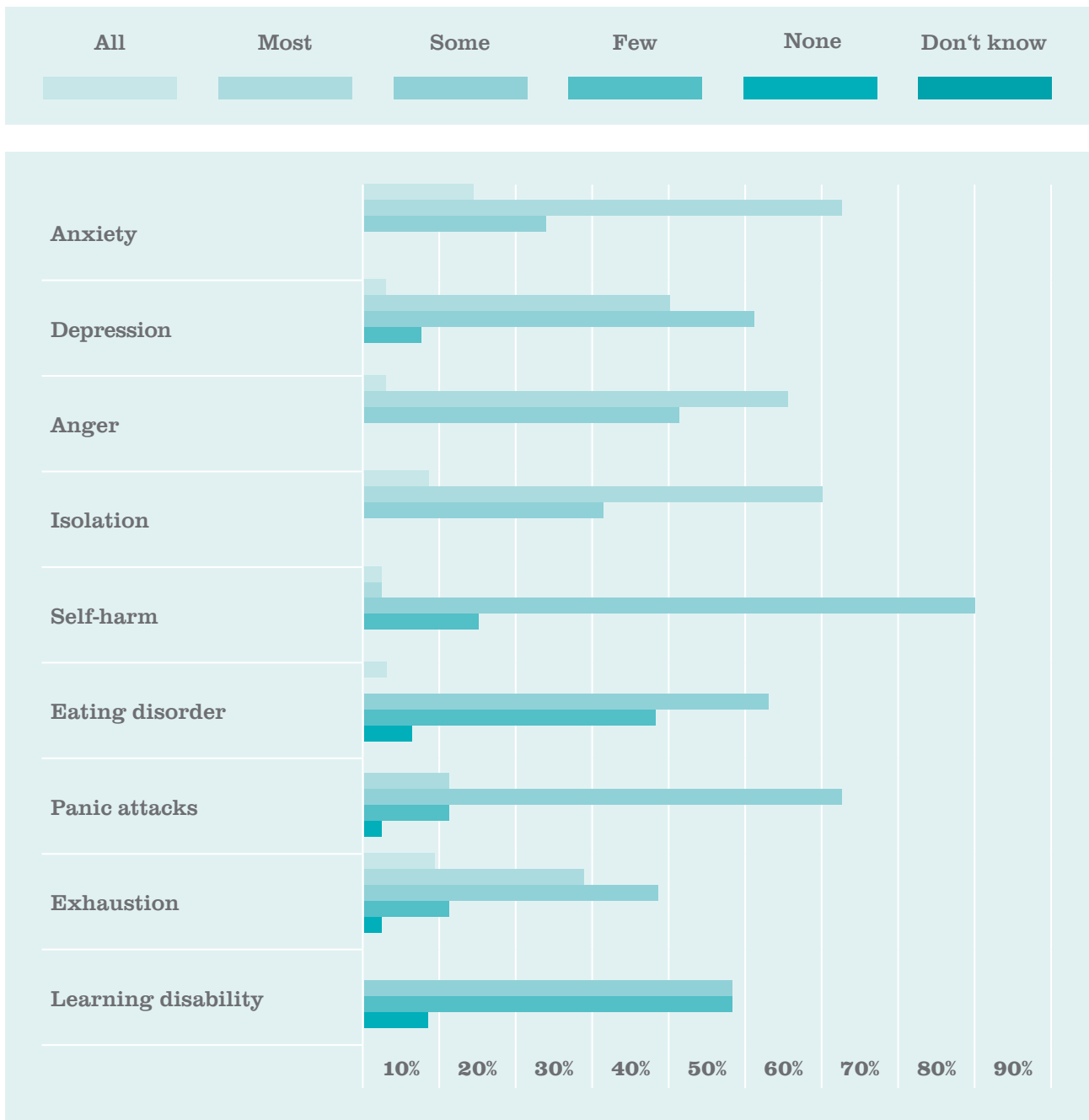
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<sup>24</sup> Frank, J et al (1999) *On Small Shoulders: learning from the experiences of former young carers*: The Children’s Society: London.

<sup>25</sup> The support provided to young carers in England, Office of the Children’s Commissioner, December 2016.

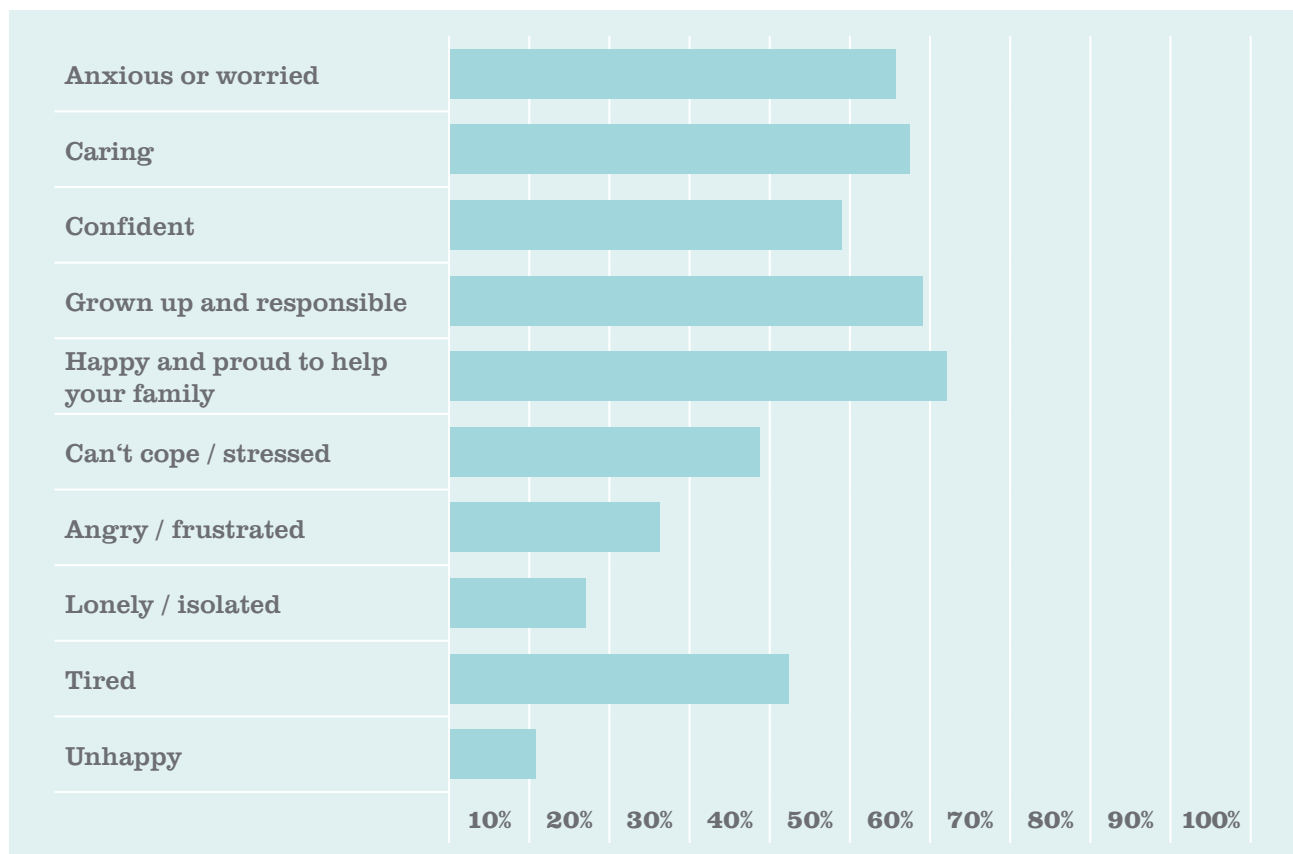
<sup>26</sup> <https://publications.parliament.uk/pa/cm201617/cmselect/cmhealth/849/849.pdf>

**Fig 1.4 In your opinion, how many of the young carers you work with have/had the following issues?**



These statistics are startling and our findings from our young people's survey provide even more evidence that the impact of caring can lead to emotional health issues. Over 50% of our young carer respondents told us that being a young carer had impacted on their emotional and mental health, 56% said that being a young carer made them feel anxious or worried and just under 40% said it made them feel like they couldn't cope. A quarter said they felt isolated as a result.

**Fig 1.5 Does being a young carer sometimes makes you feel?**



Emotional health and wellbeing is an issue that was consistently raised in our young carer focus groups. In a group in Preston, one young carer told us that as a result of being a young carer, she had social anxiety and suffered regularly from panic attacks. She struggled to leave the house on her own and in her own words, she put this down to “*not having had the opportunity to go out and be a young person*”.

Another told the group that she suffered from depression in secondary school and stopped eating and socialising. She felt that she was not bothered about anything else apart from caring, was “*in a bubble*” and the focus was wholly on her role in the home.

A third young carer said she had also suffered from panic attacks, anorexia and had self-harmed and had experienced violence around her caring role. She dropped out of school in year ten and ended up going to a referral school and then dropped out of mainstream college. She told the group that “*Every day I go home wondering will I have to call the police, what will happen today?*” She said she constantly felt stressed and anxious.

This evidence is also backed up by the survey of Barnardo’s practitioners where 76% felt that most or all of the young carers they worked with suffered from anxiety, anger and isolation. **All practitioners had worked with young carers who self-harmed, 97% who had panic attacks and 94% who had eating disorders.**

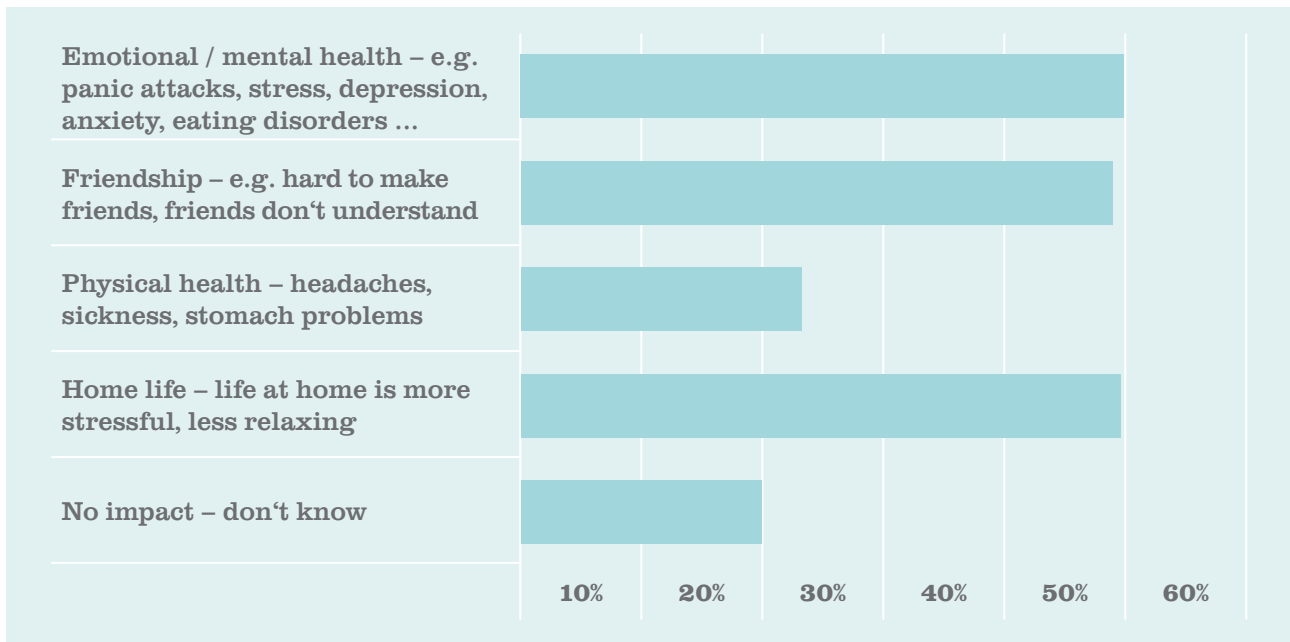
In another focus group in Preston, young carers were asked to write down how being a young carer made them feel, examples of what they wrote included depression, anxiety, self-harm, eating disorders, panic attacks, stressed out, unsupported and consumed by caring.

A young carer in a Liverpool focus group said that he rarely left the house except to attend school and spent all his time caring for his mum.

A 16 year old female young carer who had been caring for her mother with mental health issues since she was 10 told us that “*It sucks to be depended on with no support or freedom*”.

In Newcastle, a 12 year old girl told the group that she “*finds it hard to keep calm – if your mam asks you to do too many things, I try to keep calm – I don’t have five hands at the same time*”.

**Fig 1.6 Has being a young carer impacted on the following areas of your life**



**Recommendation 29**

Schools should have regular counsellor time available specifically for young carers particularly in times of increased stress such as exam time.

**Recommendation 30**

CAMHS must take a whole family approach and ensure that they examine how the burden on young carers can be relieved by working closely with other agencies involved with the adult.

*“Before being supported by Barnardo’s, I felt that I was stuck in the house isolated and lonely. I had no friends that understood why I had to look after my mam all the time. The only people I had any regular contact with was mam and my brother.*

*When I got referred to Barnardo’s, I had nearly dropped out of college because it was too stressful balancing college with caring for my mam. They supported me to reduce my caring role so I could complete my course and have time for myself.*

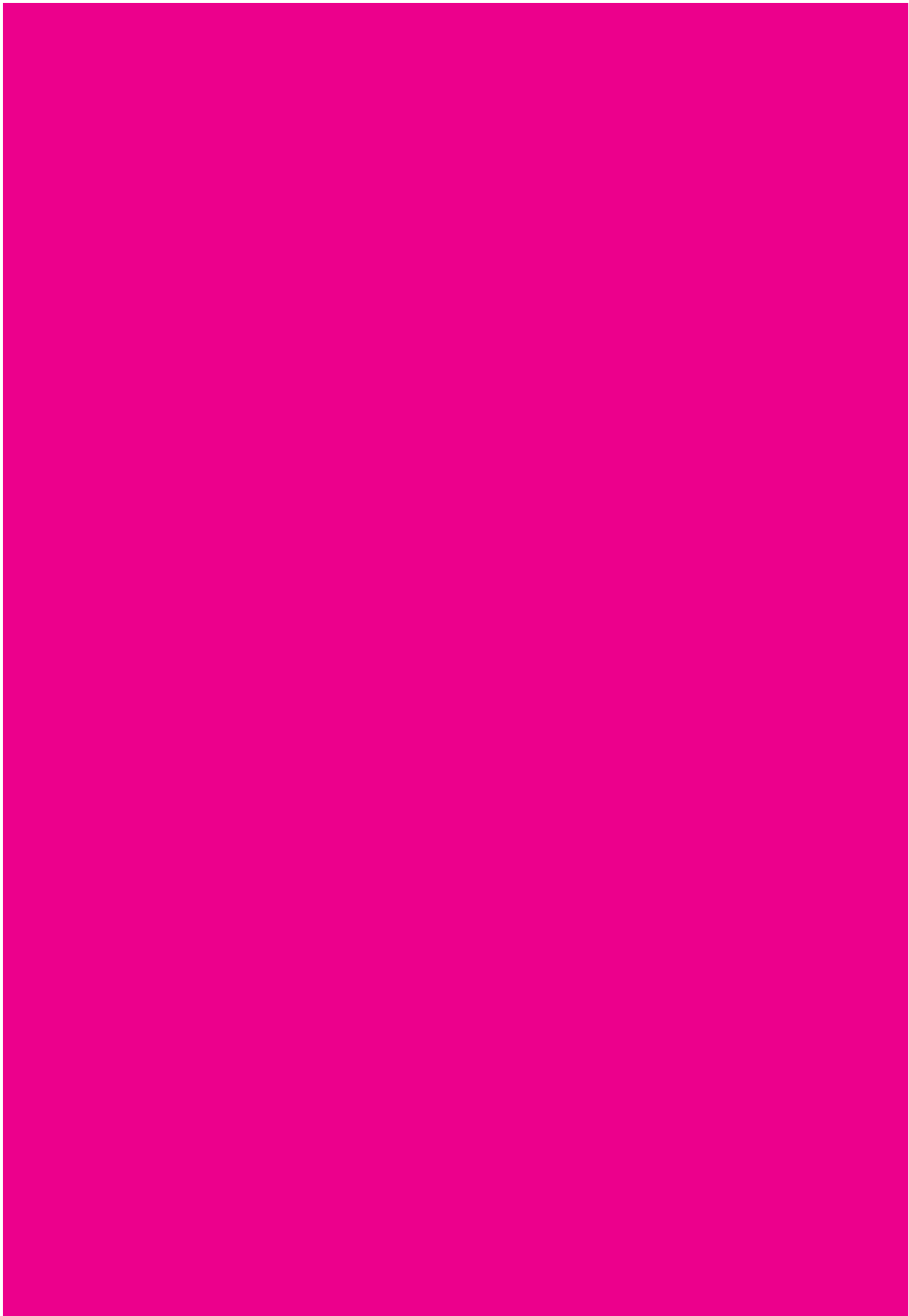
*They helped me to see myself as a priority and have a future outside of caring. In doing this they supported me to be a better role model for my brother who I am also the primary carer for. This support has allowed me to develop my career as a teaching assistant at my brother’s school.*

*To help me feel less isolated they got me involved in the structured groups so I could meet other young carers. Recently my mam passed away and the service supported me practically and with the grieving process.*

*If I hadn’t been supported by Barnardo’s, I wouldn’t have seen my own potential or had the motivation to achieve what I have. I would still have been a young carer – isolated and alone.”*

*(Young Carer, aged 24)*







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## 5. Relieving the burden of care

*“Better resources for the cared-for person who will often need support in the home is simply not available due to funding and austerity” (Barnardo’s practitioner on why young carers are still shouldering the burden of care).*

The above quote is startlingly bleak. Identification and support, though crucial, are only part of the action needed to solve the crisis for young carers. We also need to reduce the amount of care they are doing. Far too often, a combination of funding pressures, uncoordinated agencies and a lack of training means that young carers that are identified get no help with the burden of care they are carrying.

Barnardo’s joins others in celebrating the caring and considerate young people who all over the UK are caring for their loved ones over their own needs, but all too often this is used as an excuse for inaction. The reality of young carers today, is young people in their thousands sacrificing their future and their mental health to cover the failures of the agencies responsible.

In the DfE’s guidance document *Working Together to Safeguard Children 2015*, it clearly states that agencies must “*identify and be alert to the potential need for early help for a child who is a Young Carer*”. This guidance is not being followed frequently enough. Each and every young carer should be seen as a red flag by the agencies involved and quickly lead to action to address the situation. No child or young person should be put in a position where they are having to carry out inappropriate caring roles. Whenever a young person is found to be doing this, all agencies must look immediately at how they can reduce and remove that role so that child can have the same life chances as their peers.

To reduce the care level undertaken by the young carers, it is vital that identification is quickly followed by action by the agencies that should be providing the care. Drawing on the interviews with practitioners, focus groups with young carers and the YouGov survey, Barnardo’s has identified actions in five key areas to reduce the burden on the young carer: Multi-Agency involvement, Whole Family

Approach, Rights of the Child, Proactive Mental Health Services and Financing.

**Multi-agency involvement** often leads to inaction and disagreements on roles. It is time to put the young carer first and ensure that a multi-agency, multi-action approach is taken with young carers placed at the centre. In particular, adult social care needs to ensure they provide more appropriate support for that adult so that the impact on a caring child is reduced.

When separate agencies do separate assessments only a few young carers may meet the threshold for support from each single agency. However when all the different needs of young carers and those they care for are put together, the cumulative impact on the family can be far more substantial. As highlighted in our examples of good practice, there are examples of where a multi-agency approach is working effectively:

- Barnardo’s Action with Young Carers is a Liverpool wide community-based service that ensures young carers and young adult carers in Liverpool are identified and can receive a carer’s assessment, support plan, and review under the statutory duty of the Council. The service is commissioned through Liverpool City Council and jointly funded with the Clinical Commissioning Group with additional funding from Barnardo’s and Mersey Care NHS Trust.
- In Leicester, the CCG, the Carers Centre and Barnardo’s launched a joint initiative to identify young carers and help them receive the health support they need. This joint working will inevitably lead to a better identification and help relieve the burden of care on young carers.

**Whole family approach** has the best outcomes for young carers. A caring role does not exist in isolation, it is part of a bigger picture which needs to be addressed. If agencies only work with the young carer in isolation they are simply enabling that caring role to continue without questioning what interventions are necessary to reduce the caring role and its impact. Whole family working will make a long-term difference, building resilience within families and reducing the dependency on multiple

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service interventions and reducing the role and emotional impact on the young carer.

Article 12 of the United Nations Convention on the **Rights of the Child** expresses that young people “*have the right to an opinion and for it to be listened to and taken seriously*” It says that the opinions of children and young people should be considered when people make decisions about things that involve them, and they shouldn’t be dismissed out of hand on the grounds of age. It also says children and young people should be given the information they need to make good decisions.<sup>27</sup> This is particularly pertinent when it comes to young carers being involved in the drawing up of support and care plans for the cared-for relative. Young carers must be consulted not only because they are almost always the person who knows the cared-for person the best and what works for them, but also because they have a right to be involved in decisions that directly impact them.

**Proactive Mental Health Services** are also important. Parents with mental health difficulties need more support but there are innumerable barriers to accessing this. Many families do not meet eligibility criteria so children just have to ‘get on with it’ and provide the care instead. Increasing early help plans could be used to co-ordinate support between agencies and tackle vulnerabilities before they reach crisis point.

**Financing** is also key. The extended period of austerity and cuts to the financial support for vulnerable families is having a major impact and reducing the ability of the 2014 legislation to change the lives of young carers.

Too many young carers provide care because there is not the funding available to provide the support that families need. Care packages are too costly and once they are assessed, many families then refuse them as they cannot afford to pay. In addition, thresholds have risen so many families who are not entitled to support are still in great need and their children take this burden on.

### **Recommendation 31**

Adult social care need to prioritise finding additional support for families with young carers including improved working and information sharing within adult services and proactively supporting parents to access appropriate services rather than relying on care within the family.

### **Recommendation 32**

When adult services draw up support plans for the cared for person, the young carer must be consulted and involved in decisions that will impact on them as expressed in article 12 of the United Nations Convention on the Rights of the Child.

### **Recommendation 33**

Adult social care and health services should be more family friendly and look at the needs of the family rather than seeing the person who is ill in isolation.

### **Recommendation 34**

Local authorities should work towards an increased number of early help plans in order to ensure that young carers are identified earlier and support is put into place within the family at the earliest opportunity.

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<sup>27</sup> Article 12, UNCRC , United Nations.



## 6. Conclusion

It is clear from each of the surveys the major life changing impact being a young carer can have. Whilst many are proud of their role, constant care work inevitably impacts on exam results, with many young carers paying the price for their dedication by reducing their future options and giving up the chance to make full use of their academic ability. There is also clearly a big impact on mental health, with even those who are proud of being a young carer indicating an impact.

It is vital that schools step up their efforts to support young carers but also, local authority commissioners, health services and all agencies involved in adult and children care. This report lays out specific recommendations

for each sector that education, health and local and national government agencies can adopt.

It has been over ten years since Barnardo's first looked at the plight of young carers. Since then there has been much progress – including legislation, increasing awareness of the issue and rising identification of families in need. But despite these advances, we find the support and practical help to young carers is still woefully low a decade on. If we are to avoid another generation of young carers sacrificing their future for the ones they love, we need concerted action by politicians and professionals to ensure we relieve the immense burden from such young shoulders.

**Fig 1.8 Word Cloud of some of the comments from young carers about their experiences with Barnardo's**



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# Appendix 1

## Report Recommendations

### Recommendations to Government:

Using the findings from the *Making a Step Change: Putting it into practice project*, any Government strategy or green paper on carers should include a review of the legislative changes in the Children and Families Act and the Care Act 2014 and the impact they have had on young carers and young carers' services. (Recommendation 1)

### Cross-cutting recommendations:

Local authorities and other stakeholders should co-ordinate an awareness raising campaign undertaken within communities, pre-schools, leisure centres, churches, youth clubs, mosques and other religious places to raise the profile of young carers and the issues they face. (Recommendation 3)

As a particularly vulnerable and often overlooked group, schools, local authorities, health services and young carer services need to work to identify, engage and provide specialist support for BAME young carers in order to break down barriers and reduce the stigma and fear of agency involvement within these communities. Services need to be accessible and visible and work to overcome any language and cultural barriers that may lead to BAME families not seeking support. (Recommendation 13)

### Recommendations to the NHS and other health services:

Hospitals should ensure that when someone is discharged from their care, there is an opportunity for the question of who will support the adult at home to be asked. This should be recorded and shared with other agencies to ensure that young carers are being identified, supported and are not slipping through the net. (Recommendation 4)

GPs should ensure that when they are seeing parents with long term illnesses, disabilities, mental health and drug/alcohol dependency issues, a thorough assessment is made of the

children living within the household and that clear pathways are put into place to refer these young people to the relevant services when necessary. (Recommendation 5)

Training on spotting the signs and asking the right questions should be provided for GPs, drug and alcohol support services and adult mental health services. (Recommendation 6)

CAMHS must take a whole family approach and ensure that they examine how the burden on young carers can be relieved by working closely with other agencies involved with the adult. (Recommendation 30)

### Recommendations to local authority commissioners, adult and children's social care and other agencies:

Local authority commissioners and agencies must ensure that all services who work with adults are also aware and trained on the impact the adult's condition/situation has on any young people and are asking the right questions to ensure the young person is identified to receive the help they need. (Recommendation 2)

Local authorities need to reassess funding structures to ensure that the focus and funding is not just on the identification and assessment of young carers but also on sustainable and worthwhile support. (Recommendation 14)

Local authorities and agencies must have clear embedded pathways for young carer support and improve cross partnership working between all children and adult services. (Recommendation 15)

Local authorities should appoint a designated officer within adult social care with responsibility for young carers and transition assessments and support to ensure that there is a consistent point of contact for families and other agencies. (Recommendation 16)

All local authorities and agencies need to adopt an outcome focussed follow-up approach rather than referring young carers on and then closing the case. (Recommendation 17)

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Agencies must work together to provide joint, on-line support for young carers recognising this is a preferred and accessible method for many young people and how they would prefer to receive support. (Recommendation 18)

Local authority commissioners should look to create more Young Carer Councils as they are an excellent way to bring young carers together and help them feel empowered. (Recommendation 26)

Peer support and respite is vital when supporting young carers and where possible local authorities should make this available to young carers. (Recommendation 27)

Local authority commissioners should look to provide specific and appropriate support for young carers under the age of nine. (Recommendation 28)

Adult social care need to prioritise finding additional support for families with young carers including improved working and information sharing within adult services and proactively supporting parents to access appropriate services rather than relying on care within the family. (Recommendation 31)

When adult services draw up support plans for the cared for person, the young carer must be consulted and involved in decisions that will impact on them as expressed in article 12 of the United Nations Convention on the Rights of the Child. (Recommendation 32)

Adult social care and health services should be more family friendly and look at the needs of the family rather than seeing the person who is ill in isolation. (Recommendation 33)

Local authorities should work towards an increased number of early help plans in order to ensure that young carers are identified earlier and support is put into place within the family at the earliest opportunity. (Recommendation 34)

## **Recommendations for schools & education services:**

All primary school, secondary school and college application forms must have a tick box to give parents the opportunity to inform the institution that their child is a young carer in advance of them starting. Transition arrangements should also be put into place between schools to ensure that support is consistent. (Recommendation 7)

Schools must ensure that there is a designated member of staff responsible for young carers and that their name is published on their website. (Recommendation 8)

There should be mandatory training for all teachers to spot the signs of young carers provided both on teacher training courses and within schools. (Recommendation 9)

All schools should have a young carer's policy which is reviewed regularly. (Recommendation 10)

Partnerships between schools and young carer services to be established in order to ensure that communication and support is improved for young carers. (Recommendation 11)

More schools should sign up and utilise the Carers' Trust and the Children's Society's Young Carers in schools programme, anti-bullying training package and awards scheme. (Recommendation 12)

There should be more support in schools and a better understanding by school staff of the impact caring has on a young person. For example by:

- Allowing young carers extra time with homework & provision to sit exams at home
- Allowing young carers to use their mobile phone when needed
- Being more understanding if young carers are late or miss school
- Providing young carers with a card that can be shown to teachers in order to identify them quickly (Recommendation 19)

Schools must raise awareness about young carers and their situation to other children to reduce stigma and shame through assemblies, posters, classroom activities, speakers and PSHE lessons. (Recommendation 20)

Schools should improve outreach work and get to know the families involved and their issues better in order to fully support the young carer. (Recommendation 21)

Schools must look at providing peer support within the school day to give young carers the opportunity to meet up with each other. (Recommendation 22)

Career's advisors within schools and externally need to be trained to be aware of the challenges young carers face when making decisions about their futures post-secondary school and must

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be able to offer relevant advice and support.  
(Recommendation 23)

More partnerships between young carer services and higher education institutions should be established as they are proving to be effective at breaking down the barriers many young carers face at universities. Further engagement should be sought with Universities UK and other umbrella organisations to extend this effective working across the country.  
(Recommendation 24)

Employment, training and skills providers and advisors should be fully trained in the issues young carers face when seeking employment in order to ensure that they are properly advised on their options and know of the opportunities available to them. (Recommendation 25)

Schools should have regular counsellor time specifically allocated for young carers particularly in times of increased stress such as exam time. (Recommendation 29)

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# Appendix 2 of secondary school, college or university

## Barnardo's YouGov survey of over 800 teachers:

- 75% of educators and a staggering 81 % of head/ deputy head teachers think more should be done within UK schools to support young carers.
  - 34% of all teaching professionals and 48% of head/ deputy head teachers think there are young carers at their school who are not sufficiently supported.
  - Only 13% of teachers think schools are doing the right amount for young carers.
  - 45% of secondary school teachers said they did not feel confident they would recognise a young carer and over a third (36%) said they did not feel confident about how to refer young carers for external support.
  - More than 9 in 10 of all teachers felt that caring responsibilities could result in young carers being late or absent from school and that it is difficult for young carers to keep up with work.
  - 1 in 3 three teachers admitted they didn't think their school had any particular ways to support young carers or that there were young carers at their school who were not sufficiently supported (31%).
  - 26% of head/ deputy head teachers and less than one in five teachers said training on the issues young carers face were covered on teacher training days.
  - Less than 1 in 8 teachers said there was a young carers policy at their school and just 1% said that their school had a young carers card that could be used to quickly explain their circumstances to teachers.
  - Only 26% of teaching professionals surveyed said there was a mechanism for identifying young carers at their schools and only 19% said their school provided any training on young carers to teachers.
- 22% of young carers were identified and referred by a parent, 15% by a teacher, 15% by a social worker and only 5% by a GP.
  - 45% of the young carers support their siblings and over 80% of them are caring for their mum.
  - 90% of young carers were caring for someone with a physical disability, a mental health issue or a long-term health issue.
  - Over 50% of young carers said that their emotional health and wellbeing had been impacted by their caring role.
  - 56% said that being a young carer made them feel anxious and worried.
  - 67% of young carers said that caring made them feel tired in lessons.
  - Over 25% (20 young carers) said that they undertook over 30 hours of caregiving a week. Over 30% of the young carers spend over 20 hours per week providing care - more than half the hours of a full - time job.
  - 50% of young carers above school age reported being a young carer had either prevented them from going to university or had caused them to drop out of secondary school, college or university.

## Barnardo's survey of young carers:

- Two thirds of the young carers stated that they began caring whilst they were still in primary school and 1 in 8 had started caring at the age of 5.

## Survey of Barnardo's practitioners:

- 100% of those surveyed told us that some of the young carers they worked with had suffered from anxiety with nearly 15% saying this affected all of their young carers.
- 100% of the practitioners had worked with young carers who had depression and felt isolated.
- 100% of respondents had received referrals from young carers under the age of 8.
- 95% cited that schools can help with the identification of young carers and the engagement with their families.
- 100% of the respondents said that young carers experience difficulties balancing their caring and school work.



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