

**Findings from a focus group of young carers into the health and social care services they use**

## Executive summary

This report presents findings of a focus group session of 13 'young carers', aged 7-19, run by Healthwatch Reading in December 2013.

Young carers are children or young people 'who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled, or misuses substances'.

Healthwatch Reading aimed to find out which local health and social care services, young carers use, and their experience of these, in order to indicate to health and social commissioners what may or may not be working for young carers and to identify issues that might need exploring in larger studies in the future.

### Key findings:

- Young carers' main responsibilities were helping with food shopping, and providing emotional support to parents or siblings.
- The services/support used by young carers (ranked from most to least) were: young carers' after-school groups, social workers, teachers, friends, the Internet, school nurse, neighbour, playworker, and a youth club.
- None of the young carers said they had used or had contact with a GP in relation to their young carer's role.
- The most popular support was young carers' groups; young carers gave mixed reviews of the support from social workers and teachers.
- Top of the young carers' 'wish-list' for improvements, is a desire for their relatives to be better, for home improvements to aid mobility of relatives, care worker assistance to go on family trips away, and more school-based support, especially to help tackle bullying from peers.

### Key recommendations:

- Reading Borough Council (RBC) should continue to fund young carer's groups, and if possible, expand capacity, to cut waiting lists and reach more children.
- Education, health and social care leaders should hold talks about the possibility of increasing school-based support to young carers, such as increased school nurse availability, support workers and/or young carers' clubs based at school, information talks at assemblies and/or in PHSE lessons, and policies on teacher identification/referral/management of young carers among their pupils.
- Berkshire West Clinical Commissioning Groups (CCGs), which oversees carers' health issues on behalf of Reading's two CCGs, should commission a study into the health needs of young carers, to identify any unmet needs and service gaps.
- Older young carers should be given support as they transition into becoming adult carers.

## Introduction

This report presents findings of a focus group of 13 'young carers', run by Healthwatch Reading in December 2013.

Healthwatch Reading launched this project in the wake of increasing national concern about rising numbers of young people taking on a caring role in their families. Healthwatch Reading also has a remit to seek out the views of children, whose views on health and social care have traditionally been underrepresented.

Young carers are children or young people 'who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled, or misuses substances'. They become vulnerable 'when they the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances'.<sup>1</sup>

The most recent local research on carers - the *Carers Scoping Report*, commissioned by Berkshire West CCGs - was circulated in September 2013. It outlines current local provision by health, social services and charities and cites research suggesting young carer numbers have been hugely underestimated and need to be recalculated with a new formula.<sup>2</sup> Applied to Reading, the formula suggests there are potentially 4,009 young carers (12% of all children) in Reading.

Berkshire West CCGs' report concluded that 'levels of caring are now known to be far higher than previously thought so there is a significant shortfall in provision and a great deal of unmet need'. These shortfalls include: 'agencies working together to identify and support carers, including young carers', 'improved support for young carers in transition to adulthood, and for young adult carers' and 'more opportunities for carers to help shape policy through consultation'.

According to Reading's latest health profile, known officially as the Joint Strategic Needs Assessment<sup>3</sup>, 421 children were identified as young carers in Reading between April 2012-2013. This was a 467% increase in numbers from the previous three years. RBC provides three weekly respite clubs for young carers, which can take a total of 90 young carers. The clubs have waiting lists.

---

<sup>1</sup> Frank J. & Mclarnon J. (2008). Key Principles of Practice for Young Carers and their Families. The Children's Society

<sup>2</sup> <http://www.bbc.co.uk/news/education-11757907>;  
<http://www.nottingham.ac.uk/news/pressreleases/2010/november/youngcarers.aspx>

<sup>3</sup> Reading Borough Council (2013-2014) <http://jsna.reading.gov.uk/wider-determinants-health-vulnerable-groups/vulnerable-groups/carers-adult-young-carers/> Documents section *Ageing Well Carers Adults & Young Carers*.

## Project aims

The focus group aimed to identify:

- what kind of tasks or responsibilities young carers in Reading are carrying out;
- what services in Reading those young carers come into contact with in relation to their carer role, and what kind of experience they have had with those services;
- any suggestions from young carers about what kind of support or services they want in the future to help them with their carer role.

It is hoped the findings will be used to inform larger pieces of research to confirm where there are unmet needs and service gaps, and/or to inform any future review of support provided to young carers in Reading.

## Methodology

Healthwatch Reading was aided by RBC's young carer's coordinator in identifying potential focus group members and passing on Healthwatch consent forms to young carers' parents/guardians.

The coordinator and one of her colleagues also attended the focus group - held at Healthwatch Reading premises - so that the 13 children who attended were accompanied by people they trusted and who could manage any sensitive topics or behaviour issues that arose.

An initial exercise explored what kind of tasks or caring roles the children carried out at home. The children were then split into three small groups, facilitated by Healthwatch Reading staff, to complete charts on which local health and social care services they used, and their experiences of these. Marker pens and a variety of stickers (with smiley or sad faces, or ticks or crosses) were offered so children could choose how to indicate whether their experience was positive or negative. Staff also took notes.

The children were then brought back together for a whole group discussion on what things they would like in an ideal world to help them with their young carer's role.

## About the young carers

The young carers ranged in age from 7-19, with most around the age of 11. Some were sibling groups.

Their home circumstances included siblings or parents with profound physical disabilities, conditions or injuries and parents with social or other issues.

All of the children had been attending an RBC-run young carer's group regularly for at least 12 months.

## Findings

(See Appendix 1 for charts used in the focus groups and all the comments captured)

### Responsibilities

The young carers shoulder both an emotional and practical burden in their caring role, carrying out a variety of household tasks and emotional support:

9 help with food shopping

6 comfort/listen to their mum/dad/sibling when then are sad/angry/unwell

5 help with washing up

4 do laundry

4 get younger siblings ready for school

2 help mum or dad get dressed.

### People/professionals/services young carers have been in contact with about their carers' role

10 use a youth worker/young carer's group

9 have seen a social worker (or family worker)

7 have spoken with teachers

5 rely on friends

4 use the Internet

1 had contact with a school nurse

1 was supported by a neighbour

1 had seen a playworker

1 used another youth club

None had seen a GP

## How the young carers felt supported by the various services

The young carer's groups appeared to offer the most positive experience, with feedback such as "youth workers help and point you in the right direction", or "couldn't manage without it".

Social workers and teachers had a mixture of positive and negative feedback given about them.

Some children described how they trusted teachers: "I felt I could tell her [the primary school teacher] how I was feeling", while others, particularly at secondary school level, felt that some teachers were not sympathetic: "She asked why I hadn't done my homework. I told her I have to look after my mum, I've literally got no time. She said, 'That's no excuse'." One child described a blunt attempt by a teacher to probe their home life, who asked, "Are your parents beating you?" [before she had been officially identified as a young carer].

Social workers were praised by some children for spending time listening to their concerns: "She talked to Mum a lot, but also to us", while others reported lack of follow-up: "She only came once."

Friends were described as a great source of support: "He's a good friend, helps me out, backs me up with bullying. Keeps things confidential", "We sometimes meet outside of school, can help to go to when things are tough at home".

The feedback given on interaction with a school nurse was positive: "She invited me in for a chat. I told her I was being bullied. She took me out of lessons and played games." Another child noted: "I don't know who she is" [which echoes findings of a separate Healthwatch Reading survey of 170 secondary school pupils, due to be published in July, which showed 58% did not know or were unsure how to contact their school nurse].

None of the young carers had had any contact with a GP about their young carer's role. One child even asked during a small group discussion, "What's a GP?"

## The wishes of young carers

When asked what they most wanted, which would improve the support they received, young carers responded by calling for improvements for those they cared for, rather than themselves: "Help my sister get better, be 'normal'", "Make my house easier for my dad to get around [such as a stairlift]".

Young carers also wanted more opportunities to go on family trips, through the support of an extra care worker to come with them.

When prompted further to suggest other things that would help them personally, young carers talked about more school-based support, such as:

- teachers helping them with the bullying they experienced from other pupils
- more access to school nurses

- the creation of a school-based young carers support worker they could turn to
- free school meals - one child described how their family missed out on free school meals because they were 23pence over the threshold limit.

Earlier access to information about the young carers role, to help them identify their role and seek out help, would also be useful, the young carers said.

Children about to move above the age threshold of 19, for council-funded young carers support, also wanted help moving into the adult carer realm. One expressed an interest in volunteering to work with young carers.

One child also wanted health and social care professionals to remember to arrange support for children when their mum or dad went into hospital for surgery.

## Findings

Healthwatch Reading notes how willing the children were to talk freely about their situations. The older teenagers in particular showed a good deal of insight into their home life and the impact this had on them, and could describe the coping strategies they used. This was often due to the support they had received at young carers groups about coping with their lives.

One of the participants asked for, and was able to be given, time alone with a Healthwatch Reading staff member to discuss her situation and concerns in private.

It became clear from the focus group that the eldest siblings in families shoulder a greater burden than their younger siblings at home and are at potentially greater risk of becoming stressed, angry or upset. Not only do they often take responsibility for a lot of practical tasks [including some which could be viewed as inappropriate - such as a teenager having to help put the parents underclothes on and off], they also may be expected to take on a quasi- parental role with younger siblings.

One of the older children also expressed anxiety about the imminent loss of support from the young carer's club, once they became too old under eligibility rules to attend. That young person felt they would lose all their friends, as well as losing the professional support of the young carer's coordinator, who knew and understood them and the history of their young carer's role. The prospect of 'starting again' as an adult carer was daunting for this young person.

It was striking that none of the young carers reported any contact with a GP, and had had little contact with a school nurse - most of their interaction was with youth workers, teachers or social workers. This highlights a health gap for these children, especially given that previous research has shown that young carers' health and wellbeing can be impacted by feelings of stress, anxiety, depression,

panic and problems such as poor sleep, risk of self-harm and neglect of their own health.<sup>4</sup> A 2002 study has also found that carers are over twice as likely to have mental health problems if they provided substantial care of more than 20 hours a week.<sup>5</sup>

Another message that came through vehemently from children in the focus group was the disappointment or anger towards some teachers who appeared not to know, understand or accommodate the impact of the caring role the children endured at home. Some of the children were also desperate for teachers to adequately deal with bullying that they might receive from their peers at school, because of their overall vulnerability. At their best, some young carers described schools as a place where they could find trusted people to talk to, and have a break from their home responsibilities.

The focus group findings represent a snapshot of experience of a small number of young carers but may give health, social and education commissioners and providers ideas for topics to explore more widely in larger pieces of research.

Healthwatch Reading also spoke to or researched services outside of Reading to see how they supported young carers. Initiatives include:

- Young carer's services holding talks at secondary school assemblies to encourage identification and self-referrals - some Year 10 pupils spoke about their own experience to their peers.
- Young carers coming out of classes for an afternoon per week, over a half term, to receive support sessions.
- Older young carers being offered 'taster' vocational sessions at a local college to overcome their low career aspirations.
- Young carers writing a play about their experience, which they staged at a local library.
- A school for children with learning disabilities running regular courses for their pupils' siblings, over two consecutive weekends, to give them a break, a safe place to share concerns, and strategies for coping.
- A Scouts group recruiting and supporting young carers.
- The commissioning of an NHS-funded study into the health of an area's young carers, which showed that 35 per cent of the 87 respondents felt their health had worsened due to their caring role; eating disorders, low physical activity, and injuries caused by their caring role were also reported.

---

<sup>4</sup> SCIE (2005) Research Briefing 11: The Health and Well-being of Young Carers; London: SCIE.

<sup>5</sup> Arksey, H; Baldwin, S; Harris, J; Newbronner, L; Hare, P. Services to Support Carers of People with Mental Health Problems (2002) [http://php.york.ac.uk/inst/spru/research/summs/carers\\_mhprobs.php](http://php.york.ac.uk/inst/spru/research/summs/carers_mhprobs.php)

## Recommendations

- RBC should continue to fund young carer's groups and if possible, expand capacity to cut down current waiting lists and reach more children.
- Any extra funding secured by RBC's young carers project through other sources (such as lottery money or business donations) should be prioritised into paying for day or longer trips away for young carers and/or their families.
- Education, health and social care leaders should hold talks about the possibility of increasing school-based support to young carers, such as increased school nurse availability, school-based support workers, school-based young carers clubs, information talks at assemblies and/or in PHSE lessons, and policies on teacher identification/referral/management of young carers among their pupils.
- CCGs should commission wider research into the health needs of young carers in Reading to identify unmet needs and service gaps.
- Older young carers should be given support as they transition into becoming adult carers.

## Summary

Historically, the views of children and young people have been underrepresented when health and social care services are commissioned. Healthwatch Reading believes the focus group findings demonstrate the value of directly engaging and listening to young people. We urge commissioners and providers to give due consideration to the feedback and concerns highlighted.

## Acknowledgements

Healthwatch Reading would like to thank the 13 young carers who participated in the focus group. We would also like to thank RBC's young carers coordinator and colleague for their assistance before and during the focus group.

## Formal response from Berkshire West Clinical Commissioning Groups and Reading Borough Council.

We are grateful to Healthwatch Reading for taking the time to explore and present young carers' experiences of health and social care services in this way. The findings are timely as health and social care commissioners are currently working together to review both qualitative and quantitative data available on carer needs and provision in Reading and determine what further analysis may be needed to inform future commissioning. A joint approach to supporting carers across the care system is a key component of Reading's plans for integrated care, as set out in the

outline Better Care Fund submission approved by Reading's Health and Wellbeing Board in February 2014.

The new Children and Families Act 2014 and the Care Act 2014, strengthens young carers' rights to have their needs considered and addressed. Within our plans to prepare for the implementation of new regulations, we will be considering how we can improve young carer awareness, referral and signposting between the various professions which young carers come into contact with. We note the insights the young carers interviewed have shown into the importance to them of having their family members' care needs properly attended to by services. We will therefore be issuing a strong message about the importance of recognising young carers within a whole family approach to care in future.

The CCGs and RBC will aim to improve awareness about young carers amongst GPs, primary health care teams, social workers and teachers - at the time of their initial training and subsequently. We will encourage professionals to adopt carer-friendly practices such as flexible appointment times, and review existing services to identify alternative routes for connecting young carers to appropriate support. We are particularly committed to improving the identification, recognition and support of groups of young carers who have historically found it more difficult to access services such as those caring for someone with a mental health illness, substance or alcohol misuse problem, and those from minority ethnic backgrounds or who are lesbian, bi-sexual, gay or transgendered.

The CCGs and the local authority which serve Reading are working with other partners across Berkshire West with the intention of developing a joint strategy to address the needs of all carers. The specific needs of young carers will be addressed within this, and the agencies involved are committed to developing a joint protocol to address the needs of young carers in a cohesive manner.

Responses to Healthwatch Reading's key recommendations:

**Reading Borough Council (RBC) should continue to fund young carers' groups and, if possible, expand capacity, to cut waiting lists and reach more children.**

We are pleased to have this independent evaluation of the value placed on the young carer groups offered by RBC. The young carers clubs have been seen as a priority by both health and social care commissioners, and for the last three years the Reading CCGs have transferred funding to the local authority to enhance the young carers clubs. This funding has been used to buy equipment for the clubs, to secure resources to train volunteers, to provide additional therapeutic support, and to offer a series of short breaks to give young carers time away from their caring responsibilities.

The young carers clubs are already running at full capacity, involving 90 young carers each week. We recognise the need to address the needs of young carers who haven't been able to join the clubs because there is now a waiting list. However, we also need to ensure that limited resources are distributed equitably whilst keeping mechanisms to prioritise young people in greatest need of support

because of the strain caring places them under. We will work with young carers to find the best way to achieve this. For example, some young carers may be happy to attend groups on alternate weeks and be linked into other support in the interim. We would also want to work with partners in the voluntary and community sector to explore alternatives.

**Education, health and social care leaders will have discussions about the possibility of increasing school-based support to young carers, such as increased school nurse availability, support workers and/or young carers' clubs based at school, information talks at assemblies and/or in PHSE lessons, and policies on teacher identification/referral/management of young carers among their pupils.**

The current school nurse contract for this area is due for renewal shortly, and the Public Health team is reviewing current arrangements to shape the new contract. The Public Health team will liaise with the Children's Services teams to identify ways that young carers' access to school nurses could be improved, and how other support to stay well could be offered through the young carers clubs, such as information sessions on healthy lifestyles, sexual health etc.

The options for linking other support to the young carers clubs would depend on how those clubs are organised in future. We have had feedback previously from young carers that after school slots are preferable to clubs running within school time. However, the Healthwatch Reading report highlights several issues it would be helpful for us to seek feedback from a wider group, and the timings of clubs could be included within this.

We realise that a wide range of professionals may come into contact with young carers, and be in a position to support them or indeed to add to their burden by not understanding the impact that caring can have on them. RBC has commissioned an online training tool on young carer recognition and support, and will ensure that schools are targeted in the promotion of this tool, known as 'Young Carer Aware', when it becomes available.

The CCGs will look at ways of increasing awareness of young carers across the health system and also promote the Young Carer Aware tool to GP practices.

**Berkshire West Clinical Commissioning Groups (CCGs), which oversees carers' health issues on behalf of Reading's two CCGs, will commission a study into the health needs of young carers, to identify any unmet needs and service gaps.**

The Public Health team takes responsibility for overseeing the production of a Joint Strategic Needs Assessment (JSNA) for Reading, which then underpins health and social care commissioning. The current JSNA includes a module on carers, which sets out some key findings from evidence reviews, including that young carers are at high risk of experiencing worry, depression and self-harm.

The JSNA will be refreshed in 2014 and we will take this opportunity to develop our understanding of young carer needs and service gaps in the Reading area.

**Older young carers should be given support as they transition into becoming adult carers.**

Through the young carer clubs, one-to-one transition support is offered to young carers as they approach the upper age limit for the clubs. The focus group feedback suggests a possible gap in the services young adult carers transition to, however. We would like to explore this with a wider group to help identify future funding priorities for carer support, in particular facilitation of peer support.

*Gabrielle Alford, director of joint commissioning, Berkshire West Clinical Commissioning Groups.*

*Asmat Nisa, consultant in public health, Reading Borough Council.*

*Avril Wilson, director of education, adult and children's services, Reading Borough Council*



## **Appendix 1: Findings from focus group**

WHAT KINDS OF THINGS DO YOU HAVE TO DO AT HOME TO HELP YOUR MUM OR DAD OR SISTER OR BROTHER?



LAUNDRY.....ticked by 4 young carers



WASHING UP.....ticked by 5 young carers



GETTING YOUNG  
BROTHERS OR SISTERS  
READY FOR SCHOOL.....ticked by 4 young carers



COMFORTING/LISTENING  
TO YOUR MUM, DAD,  
BROTHER OR SISTER  
WHEN THEY ARE SAD,  
ANGRY OR UNWELL.....ticked by 6 young carers



HELPING MUM OR DAD  
GET DRESSED.....ticked by 2 young carers



SHOPPING FOR FOOD.....ticked by 9 young carers

# WHO GIVES YOU HELP, SUPPORT OR ADVICE?

	Used?	Positive Experience	Negative Experience
 <p><b>YOUTH WORKER AT AFTER SCHOOL CLUB</b></p>	10	<p>“Welcome”.</p> <p>“People are nice.”</p> <p>“Get to see your friends.”</p> <p>“Learning activities.”</p> <p>“Youth workers help and point you in the right direction.”</p> <p>“It’s the best thing.”</p> <p>“Couldn’t manage without it.”</p> <p>3 and a half smiley faces</p>	<p>“More activities.”</p> <p>“Don’t blame the whole group for some naughty people.”</p> <p>“[Want] even more fun.”</p> <p>Half a smiley face</p>
 <p><b>TEACHER</b></p>	7	<p>“Can talk about anything you need to.”</p> <p>“Really kind.”</p> <p>“Make me feel better.”</p> <p>“Listens to me.” (Pupils in years 3 and 5)</p>	<p>“Some people scary.”</p> <p>“Sometimes they get involved with things they don’t understand</p>

		<p>3 smiley faces:</p> <p>“I felt I could tell her [primary school teacher] how I was feeling.”</p> <p>“She spoke to me about how to deal with bullying.”</p>	<p>and can make things worse.”</p> <p>“Don’t understand.”</p> <p>“Don’t ask [about my home life].” (year 6 and secondary school)</p> <p>1 cross</p> <p>“She asked why I hadn’t done my homework. I told her I have to look after my mum, I’ve literally got no time. She said, ‘that’s no excuse’. I screamed at her and threw a pencil at her and left the room.”</p> <p>“The teacher asked, ‘are your parents beating you?’.” [before they knew pupil was a young carer].</p> <p>“They never did anything about it</p>
--	--	---	--

			[ongoing bullying].”
 <p><b>SCHOOL NURSE</b></p>	1	<p>1 smiley face:</p> <p>“She asked [the RBC young carers’ coordinator] to come in and talk about the young carers club.</p> <p>“She invited me in for a chat. I told her I was being bullied. She took me out of lessons and played games.”</p>	<p>“Don’t know who she is.”</p> <p>“She’s useless.”</p>
 <p><b>SOCIAL WORKER</b></p>	9	<p>“Bubbly. Makes everything fun.”</p> <p>“She was nice.”</p> <p>3 smiley faces: “The social worker bought us McDonalds.”</p> <p>“She introduced me to [RBC young carers coordinator] and then I started going [to young carers club].</p> <p>“She talked to Mum a lot, but also to us.”</p> <p>“We talked about how to stop fighting. We would play games with her.”</p> <p>“She sometimes did one-to-ones with us.”</p>	<p>“Sometimes grumpy.”</p> <p>“Sometimes feels forced [to talk].”</p> <p>“Pushy.”</p> <p>“Different person might help.”</p> <p>“Only came once.”</p>

 <p>FAMILY DOCTOR/GP</p>	0		<p>“Never asks [regarding young carer’s role] when we see him.”</p>
 <p>INTERNET CHATROOM</p>	4	<p>“Best place to chat and get to know other young carers.”</p>	<p>“Have come across youngcarers.net but didn’t use it.”</p>
 <p>HELPLINE FOR YOUNG PEOPLE</p>	0		

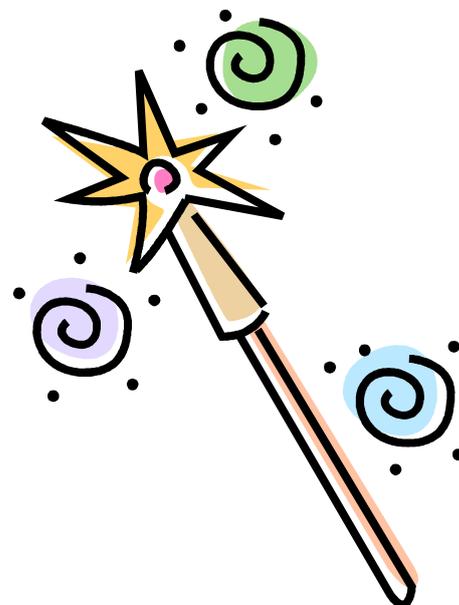


**ANYBODY  
ELSE...**

	<p>“Friends.”</p> <p>“Kickz Fairview/anger management.” (Football and youth club at Fairview centre in central Reading)</p> <p>Play-worker</p> <p>Neighbour</p>	<p>“Best friends - they know the family and what’s going on.”</p> <p>“He’s a good friend, helps me out, backs me up with bullying. Keeps things confidential.”</p> <p>“We sometimes meet outside of school, can help to go to when things are tough at home.”</p> <p>“Friend at school and the young carers club. It’s important to build trust. It helps that we are at the same club and school.”</p> <p>“Really helped me.”</p> <p>“Played and cooked with us.”</p> <p>“She’s like our nan. She looks after us.”</p>	
--	---	---	--

**WHOLE GROUP DISCUSSION -  
THE MAGIC WAND QUESTION:**

If you could change one thing to make your life as a young carer, what would it be?



**Initial responses:**

“Help my sister get better, be ‘normal’.”

“Help my mum get better.”

“Make my house easier for my dad to get around [such as a stairlift].”

“Bigger garden.”

“More space for my sister.”

“Go to Weymouth [for a trip].”

“More trips as a family.”

“Funding for additional adult/carer [to help on family holidays].”

**Further comments following more questions about initial identification, referrals, information resources and access to services:**

“Teachers need to spend a week in the school holidays going on a course about how to deal with and stop bullying.”

“Getting support after turning 19.” [When no longer eligible for young carer’s provision].

“Opportunities [for older/post-19 young carers] to volunteer to work with younger young carers.”

“Facebook page or website for young carer’s group.”

“A leaflet on ‘what is a young carer?’ to be given out to young people.”

“Access to school nurses, through drop-ins.”

“A young carers’ support worker in school, maybe a member of staff.”

“Free school meals.” [One child said her family wasn’t allowed free school meals because they were 23pence over the threshold limit].

“More family support during hospital treatment.” [One young carer said she was not offered or referred for any family support when her parent went into hospital for planned treatment].

