Department for Education

The lives of young carers in England

Qualitative report to DfE

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Overview

This report forms part of a programme of research conducted by TNS BMRB, in partnership with Professor Jo Aldridge, Director of the Young Carers Research Group (YCRG) at Loughborough University, investigating the lives of young carers aged 5 to 17 in England. This research, undertaken on behalf of the Department for Education, has comprised:

- A feasibility study to find a cost effective quantitative approach (or approaches) that can give the Department an estimate of the prevalence of young caring, the characteristics and circumstances of young carers and the impact of their caring responsibilities on their lives.

- Qualitative research to find out more about the characteristics of young carers and their families; the nature of care they are providing; the impacts of caring responsibilities and needs of both young carers and their families; experiences of support; and responses to support propositions developed in consultation with key local and national stakeholders. This qualitative research forms the focus of this report.

Background

According to the most recent census (Office for National Statistics, 2011), there are almost 166,000 young carers (aged 5-17) in England. Young carers undertake a wide range of caring roles and responsibilities, including emotional support, personal care, housework and household budgeting. While research has found that caring can result in positive impacts, there is a relatively strong body of evidence on the adverse impact of caring on health outcomes, social activity, educational engagement and employment opportunities for young carers (e.g. Aldridge, 2008; Becker, 2007). As such, children who live with and care for parents or other family members who are ill or disabled may require support in their capacity as children and/or as young carers.

At present, young carers and their families have access to a range of different health, social care and educational support services, all of which should include needs assessments that support the identification and management of adults as services users, the support needed in their role as parents and, importantly, the support needs of their children. However, a significant proportion of young carers have not disclosed their

caring responsibilities to their school, they are no more likely to be in contact with social services than are their peers, and only a minority have had an assessment of their needs or been informed about sources of help (Barnardo's, 2006; Dearden and Becker, 2004; The Children's Society, 2013). Many families do not recognise their children as 'carers' (Smyth et al., 2011), some children do not recognise or identify with the role, and there can be a degree of reluctance, even anxiety, among families in disclosing caring responsibilities.

With the implementation of the Care Act 2014 (HM Government, 2014) and the Children and Families Act 2014 (HM Government, 2014) there is now a need for local authorities to identify <u>and </u>assess the support needs of young carers, regardless of the type of support they provide.

Methodology

This research involved 22 face to face research visits conducted with young carers aged 6-17 and their families between January and March 2015. A number of purposive recruitment approaches were used to sample a broad range of young carers including: targeted engagement with gatekeepers in young carer support services such as young carers' projects and young carer respite services; and screening from an online panel. Research visits lasted 3-4 hours and used a mixture of exploratory discussions with families, observations of family interaction, in-depth interviews with children who were providing care for parents/siblings, and interviews with parents/guardian and other family members e.g. a cared-for sibling. The research with young carers, and the support propositions tested, were informed by a rapid evidence assessment (undertaken as part of the accompanying feasibility study) and 10 telephone interviews undertaken with individuals representing local authorities and national and local support organisations across England between October and December 2014. Finally, a 90-minute workshop was conducted with young people (n 9) aged 11-17 who attended young carers' projects to validate key findings on the types of support local authorities should prioritise.

Key findings

Understanding the context of caring: young carers and their families (Section 2)

- Young carers were more likely to care for a mother than a father, and lone parent families were over-represented in the sample. This is aligned with findings from previous research (e.g. Dearden and Becker, 2004)

- Cared-for parents/siblings all had a single or dual diagnoses of physical or mental health illnesses/disabilities, however these were often also accompanied by other physical and/or mental health issues that had not been formally diagnosed. Parental mental health conditions were particularly challenging for children to cope with due to the unpredictability of the nature and extent of care support needed. This unpredictability also had implications for the degree to which mental health services were able to provide timely support for parents with mental health problems.

- Parents could struggle to discuss their health conditions with their children, particularly where their conditions were complex or terminal, or where the child was young (i.e. those aged under 10 or 11). There was a clear desire among young carers of all ages to better understand the condition of the cared-for person – potentially through greater involvement in discussions held between health care professionals and their parents.

- Older young carers (those aged 16 and 17), and those in lone parent households, tended to take on greater caring responsibilities and felt more responsible for providing support than did younger carers or those children who had not disclosed their caring responsibilities. In most cases young carers stated that they were happy to provide caring support – even more personal forms of care - however there were some responsibilities, such as helping to manage household finances, where they indicated that they were less comfortable due to a lack of experience.

- School holiday periods were particularly challenging for most of the young carers due to an increase in their caring responsibilities at home and reduced opportunities to engage in other activities both inside and outside the home as compared to during term-time.

Experiences and impact of caring on children and families (Section 3)

- Caring was seen to be a very rewarding role by the majority of the young carers – regardless of age or length of time caring - bringing with it a range of positive emotional and psychological benefits. However caring also had adverse effects: anxiety, stress, tiredness, strain within family relationships, restrictions in social activities and relationships, and under-engagement in education.

- The majority of parents were keen to reduce the impact of caring responsibilities undertaken by their children particularly in respect of social relationships and school engagement. There was a clear desire among parents for their children to receive

support in making effective education transitions and in planning for the future. However, parents did not appear to be actively preparing for their child to cease caring responsibilities through explicit parent-child discussions of how caring needs could be fulfilled as their children grew older and became more independent.

- Young carers developed different coping strategies in order to lessen the impact of their caring responsibilities. Older young carers benefited particularly from social relationships, whereas younger carers benefited from sharing their feelings openly with parents and some used tools such as worry books (introduced either by parents or school support staff) to communicate their thoughts and feelings. To reduce the impact of their caring role on their education, many young carers in secondary school tried to complete homework before returning home.

- Young carers known to local services did identify with the term 'young carer'. Young carers were proud of their caring role but also recognised that it was used as a label which carried with it negative connotations. Young carers not receiving formal support services did not self-identify with the term 'young carer' and parents of these children and young people expressed concerns about their child being labelled as a young carer – a label which they felt reflected negatively on them as a parent.

Young carer needs assessments and uptake of services (Section 4)

- Formal or informal support helped reduce the extent of young carers' responsibilities, however not all parents were comfortable disclosing their condition to health and social care professionals due to a fear of the potential repercussions for their family.

- There was confusion among both young carers and their parents as to whether children had received their own young carers' needs assessment. Children and parents believed needs assessments could be improved by ensuring they were conducted promptly following disclosure, in a private setting, in a mode preferred by the child (i.e. face-to-face or by telephone), and with clarity in respect of the outcomes of the assessment.

- Young carers typically accessed young carers' services via referrals from adult/children's social care, school, or adult/children's health services. Barriers to accessing support included parental concerns about the consequences of disclosure for families (and what this would mean for their children), lack of understanding of the nature of support available, and concern as to the appropriateness or impact of interventions and support services. Conversely, early and effective communication

between professionals and families helped to allay parental concerns about the consequences of requesting/accessing support, and helped to facilitate access to young carers' projects.

- Young carers' projects were an important source of formal support and respite for young carers. Having caring in common made it easier for these children and young people to open up in conversation about caring – something that was valued by both parents and their children. Projects also provided access to fun activities, as well as information, advice and advocacy, although the nature and extent of provision varied across the projects. As young carers became older it was evident that they sought to engage with a wider peer group, and relied less on young carers' projects. Young carers and parents both expressed a desire for young carers' projects to provide support for families to spend more time together.

- Schools provided support to those children who were identified as young carers, ranging from personalised teaching/pastoral support, access to homework clubs or afterschool provision, and greater flexibility in school/class attendance. Support for young carers in school varied considerably, in some cases support reduced the emotional and educational impact of caring, but in other cases it was inconsistently provided due to a lack of shared information/understanding between teachers.

- Social workers tended to have limited contact with young carers about their caring role, although some children did have a key worker who discussed the impact of caring with them and made referrals to young carers' services. There was a high degree of distrust of social services generally, and social workers more specifically, within families who had direct experience of support from social services in the past. In these cases both children and their parents were reluctant to disclose information about caring responsibilities for fear of potential repercussions in the form of interventions that might lead to family separations.

Support propositions: views of young carers and their families (Section 5)

- Parents and young carers identified a number of factors that would promote access to support for young carers. These included: increasing the inclusivity and availability of young carers' services (e.g. greater support for younger carers and enabling access through central locations or transportation to and from services); ensuring that health and social care support services communicate the availability and nature of young carers' services quickly and effectively; standardising age appropriate activity and

information across young carers' services; and improving support for cared-for family members to help meet diverse needs.

- As part of this research, young carers and their parents were presented with a range of propositions for forms of support that may be beneficial to young carers and their families (see Appendix A).

- Young carers and their parents identified benefits from having someone to talk to about concerns, relationships and the experience of caring, including other young carers of a similar age – those with a shared experience and understanding. However, framing this in the language of 'taking a break from caring', could reduce engagement in this form of support by children and parents who do not perceive a need for a 'break'. Practical support through the provision of aids/equipment (for those families where parents or other relatives had mobility and social care needs) helped reduce the caring responsibilities of children and young people while information from professionals helped to alleviate their anxieties caused by a lack of knowledge around their parent or sibling's condition.

- Parents and young carers were keen to mitigate the impact of caring on their ability to participate fully in school, and to achieve. Young carers identified that support from teachers to complete their studies as the main way in which schools could support them. This was best achieved through teachers having a clear understanding of the nature of children's caring responsibilities and providing stronger support around stressful periods such as exams and transition points.

- Information about managing finances was most relevant for older young carers who were more likely to be providing this kind of support in families. However, younger carers also expressed an interest in learning more about money. Likewise, support with life planning was also seen by young carers and parents to be valuable support, although this was most relevant for older young carers nearing independence.

1. Introduction

Following the Care Act 2014 and the Children and Families Act 2014, from April 2015 local authorities will need to identify and assess young carers' support needs – no matter how much or what type of care they provide. To inform and evaluate the effectiveness of this new legislation a robust and up-to-date estimate of the number of young carers is required, including those who are not receiving formal support services and not identified by local authorities. Additionally there is a need for research that investigates the dimensions and characteristics of caring and the impact of these on children's lives.

TNS BMRB, in partnership with Professor Jo Aldridge, Director of the Young Carers Research Group (YCRG) at Loughborough University, has conducted a programme of research investigating the lives of young carers aged 5 to 17 in England. This research, undertaken on behalf of the Department for Education, has comprised:

- a feasibility study to find a cost effective quantitative approach (or approaches) that can give the Department an estimate of the prevalence of young caring, the characteristics and circumstances of young carers and the impact of their caring responsibilities on their lives

- qualitative research to find out more about the characteristics of young carers and their families; the nature of care they are providing; the impacts of caring responsibilities and needs of both young carers and their families; experiences of support; and responses to support propositions developed in consultation with key local and national stakeholders. The qualitative research forms the focus of this report.

1.2. Background

Young carers are those children and young people under 18 who provide regular and ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances. While many children and young people provide everyday help to family members, what distinguishes children as a young carer is that responsibilities persist over time and are important in maintaining the health or wellbeing of a family member. It is recognised that when children's caring responsibilities become 'excessive or inappropriate' and when caring affects their emotional or physical well being, education and life chances then this enhances children's vulnerability, and they should be considered children in need (Association of Directors of Children's Services,

Association of Directors of Adult Social Services, Children's Society and Carers Trust (2015).

According to the most recent census (Office for National Statistics, 2011), there are almost 166,000 young carers (aged 5-17) in England. This represents a 19% increase over the ten-year period between 2001 and 2011, although among younger carers aged 5- 7 years old there has been around an 80% increase recorded. Research has shown the caring can have a range of positive impacts on children who care for others - ranging from strengthened relationships to practical life skills – where caring responsibilities are recognised and support services are in place to support these children and their parents (e.g. Dearden and Becker, 2000). However, there is also a relatively strong body of evidence on the adverse impact of caring on children's health outcomes, social activity and employment opportunities. For example, evidence from the Young Carers Research Group has shown how caring can have an adverse effect on children's lives and transitions into adulthood, particularly when caring is long-term, unsupported and disproportionate to children's age and level of maturity (Aldridge, 2008). Research also shows that caring affects children's ability to participate in school and their decisions to continue into further and higher education (Becker, 2007). Using the Longitudinal Study of Young People in England data, research conducted by The Children's Society (2013) found that on average, young carers achieve nine grades lower overall at GCSE than their peers. It also found those caring for a parent with drug or alcohol problems appear to be most at risk, with 40% reporting at age 13 or 14 that they had missed school because of their caring responsibilities.

Research also shows the wide range of caring roles and responsibilities undertaken by children and young people including emotional support, personal care, house-work and household budgeting. As such, children who live with and care for parents or other family members who are ill or disabled may require support in their capacity as children and/or as young carers. At present, young carers and their families have access to a range of different health, social care and educational support services, all of which should include needs assessments that support the needs of adults as services users, as parents and, importantly, the support needs of their children.

Currently, young carers are no more likely to be in contact with social services than their peers (The Children's Society, 2013). Similarly, nearly four out of ten young carers (39%) have not disclosed to school staff that they are carers (The Princess Royal Trust for Carers, 2010) and only 29% have been informed about sources of help (Barnardo's. 2006). Furthermore, some families will themselves not recognise that the child or young person is a 'carer', often because they do not regard their responsibilities as unusual in

any way or outside 'normal' expectations of family obligations (Smyth et al., 2011). Many parents and children will also be reluctant to disclose the nature and extent of the young person's caring responsibilities to others, including school staff, social workers and other professionals. The reasons for this include children's fear of bullying and discrimination from peers who lack empathy towards, or understanding of, their family situation, and concerns about interventions that might lead to family separations (Aldridge and Becker, 1993). Most research studies on young carers to date have included children who are known to services. These studies have provided a rich understanding of the nature of young carers' roles in the UK and the impact of caring on children. However, we know much less about 'hidden' young carers - those children whose caring roles are unrecognised and unsupported.

Previous evidence suggests that policy and practice guidance on identifying and addressing the needs of young carers has been inconsistent and disjointed. Historically, national surveys of young carers have found only small proportions receiving an assessment of their needs (Dearden and Becker, 2004). In light of the implementation of the Care Act 2014 and the Children and Families Act 2014, and the need for local authorities to identify <u>and </u>assess the support needs of young carers regardless of the type of support they provide, this is an opportune point to build on existing evidence to better understand the dimensions and characteristics of young caring, the nature and extent of children's caring roles, and their support needs.

1.3. Methodology

This section provides a brief summary of the qualitative research methodology, which included:

- **Stakeholder interviews**: 10 telephone interviews were undertaken with individuals representing local authorities and national and local support organisations across England between October and December 2014. The interviews explored current research priorities and the impact of recent and forthcoming policy developments. These interviews served as a basis for the development of draft support propositions that were tested in the primary qualitative research and to inform the quantitative feasibility study.

- **Qualitative research with young carers and their families:** 22 face to face research visits were conducted with young carers aged 5-17 and their families between January and March 2015. These involved visits of 3-4 hours to each family using a mixture of exploratory discussions with families, observations of

family interaction, in-depth interviews with children who were providing care for parents/siblings, and interviews with parents/guardian and other family members e.g. a cared-for sibling.

A number of purposive recruitment approaches were used to sample a broad range of young carers, including young carers not receiving formal support services whose caring roles and responsibilities had not been disclosed to statutory services (e.g. who had not been identified by local authorities/support services as young carers). These included: targeted engagement with gatekeepers in young carer support services such as young carers' projects and young carer respite services; and screening from an online panel[1] to approach families whose answers to an online survey indicated a young person was providing care for a family member.

Historically, researchers have experienced challenges in engaging with children and families where 'hidden' young caring is taking place. As discussed previously, caring may be perceived as normal within a family, or families may be reluctant to disclose caring due to a fear of stigmatisation or concerns about the risk of intervention by social services. Previous research has shown that young carers who were less likely to access statutory services included children supporting a lone parent with mental ill health, or those families where substance misuse or cultural barriers existed, and in some cases where children were providing extensive or inappropriate care. Without the formal involvement of statutory services in respect of caring responsibilities there is a significant challenge in identifying and engaging families where children are providing care for a parent or sibling.

The study aimed to identify and involve young carers who were more likely to be 'hidden' (i.e. those not engaging with formal support services) through online panel data and participants of the Longitudinal Study of Young People in England Survey 2 (LYSPE2) for young people aged 15-16 years old, which asked young people about the nature of any caring responsibilities.

After review from the DfE and guidance from an independent ethical committee, the use of sample identified from LSYPE2 was not used because recruitment posed potential ethical challenges for the qualitative home visits. Parents of young

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[1] Panellists were screened through Kantar's dedicated online research company, Lightspeed Research to draw a sample of households containing 5-17 year olds who were asked whether a family member had an illness/disability and if a young person provided care to that family member.

people meeting criteria for 'carers' may not identify their children in this way and the research did not want to breach confidentiality by disclosing the young person's perceived status to the wider family when seeking informed consent.

The online panel identified five young carers who were not currently accessing formal services and agreed to participate in this research. However, is it important to note that these children are not necessarily representative of all 'hidden' young carers. Therefore for the purpose of this research we will refer to these participants as "young carers not receiving formal support services". A further 18 parents of children identified as performing caring responsibilities through the online panel were contacted to participate in this research. These parents either: (i) declined to participate in the research due to English not being a first language or parents identifying themselves as being too vulnerable or disabled to participate, or (ii) the information from the online panel was inaccurate in terms of contact information or the level of caring responsibilities undertaken by a child or young person.

- **A peer review workshop**: in order to help validate and further explore the research findings a 90-minute workshop was conducted with nine young people aged 11-17 who attended young carers' projects. These young people were all recruited with support from young carers' organisations. The findings from the research with young carers and their families were shared and discussed to validate key findings with respect to the types of support local authorities should prioritise.

Additionally, the qualitative research was informed by a **Rapid Evidence Assessment** (REA) undertaken as part of the feasibility study. This helped to provide a definition of young caring and to provide contextual information on the prevalence, nature and impact of young caring.

The recruitment criteria for the young carers and families sample ensured that the research included:

- families from different geographic areas across England, and from both rural and urban locations

- a range of different family structures, including both lone parent families and two-parent families, and families with different numbers of children

- young carers of different genders and ages ranging from 6-17 years old

- a range of diagnosed illnesses/disabilities of parent/sibling including physical conditions (e.g. cancer, diabetes, fibromyalgia, ME, MS, etc.) and mental health conditions (e.g. anxiety, depression, personality disorder, etc)

- a range of time children spent caring each week from under 5 hours, 5-15 hours to over 15 hours

- varying degrees of children's engagement with formal support services from no involvement in services (referred to as young carers not receiving formal support services) through to those involved with social services, health services and/or young carers' projects

Researchers used a topic guide and age appropriate stimulus materials (e.g. open ended questions and visual tools/approaches to enable discussion) that covered topics such as the caring experience and its impacts for both the young person and the person cared-for[2], experiences of assessment and current support provision, and responses to potential support propositions. The full topic guide and stimuli are included in Appendix B to this report.

Research ethics

All participants were provided with written information explaining the purpose of the research, reassurances of anonymity, confidentiality and the voluntary nature of the research, as well as clarity regarding disclosure in case of risk of harm. See Appendix C for further information about our approach to research ethics and the materials used with children and families. Interviews were digitally recorded, with participant consent.

Analysis and reporting

Given the nature of the qualitative methodology and the size of the sample within this research it is important to acknowledge that findings from these interviews are not generalisable to all young carers and their families. The findings from this research are, however, useful for illustrating and understanding children's and families' experiences, and for providing an indication of the dimensions of caring – the nature and extent of support that young carers and their families need.

All interviews were digitally recorded and transcribed to enable detailed analysis within and across the data. All data gathered in interviews were thematically organised and analysed using both an inductive and deductive approach. Pre-identified themes of likely interest to the research were used to organise data (e.g. impacts of caring on emotional

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[2] Elements of existing assessment tools MACA-YC18 and PANOC-YC20 were also used to enable discussion of the extent and impact of caring. Joseph, S. Becker, F. and Becker, S. (2009), Manual for measures of caring activities and outcomes for children and young people, London: Princess Royal Trust for Carers

wellbeing, social activity, family dynamics etc.), supplemented by additional themes emerging from internal analysis sessions held by researchers following a review of all transcripts. This systematic approach enabled researchers to draw out the diversity of opinions and experiences expressed by participants, as well as identify common themes across interviews.

1.4. Report outline

Following this introductory chapter, the report comprises five further chapters:

- **Chapter 2 provides an overview of the context of caring**: it explores the characteristics of the young carers in the study, the family dynamics and the nature of their care needs in order to help contextualise children's caring experiences

- **Chapter 3 presents children and families' views of caring**: including the experience of care-giving and care-receiving, and the impact of care-giving on various aspects of children's lives (such as social activity, health and education)

- **Chapter 4 details the engagement of children and families with support services**: it provides evidence on needs assessments and the routes into support services, the barriers and facilitators to accessing support, and children's and families' experiences of support services

- **Chapter 5 identifies additional support needs and investigates reactions to support propositions**: this chapter outlines the views of young carers and their families about unmet needs, and provides their responses to various propositions for services or forms of support that may best meet their address needs or generally improve their life circumstances

- **Chapter 6 draws together the research findings and presents key implications from the research.**

Throughout the report, verbatim quotes have been used to illustrate the research findings. They are attributed in such a way as to retain the anonymity of the participant.

The following working definition of a young carer was used in the study:

> *"A young carer is a child/young person under the age of 18 who provides care in, or outside of, the family home for someone who is physically or mentally ill, disabled or misusing drugs or alcohol. The care provided by children may be long or short term and, when they (and their families) have unmet needs, caring may*

have an adverse impact on children's health, well-being and transitions into adulthood."

For the purposes of clarity we use the term 'young carer' in this report to refer to children and young people aged 5-17 (who were included in the study). However, at times, age is an important variable/aspect of the caring experience and thus pertinent to the discussion; in which case, 'very young carers' are those aged 11 and under and 'older young carers' are those aged 15-17.

2. Understanding the context of caring: young carers and their families

This chapter will explore care-giving by the young carers within their family context, focusing primarily on young carers' perspectives. It will provide an overview of the characteristics of the young carers, the family dynamics and the nature of care needs in order to help provide context to our understanding of the experiences of young carers in England.

2.1. Profile of young carers and their families

Table 1 provides a detailed breakdown of the sample of young carers and their families across a range of demographic and family variables, including the nature of the illness/disability of the cared-for family member.

Table 1: Sample of young carers and their families

Gender and age	Position in family	No. of other siblings	Time dedicated to caring weekly	Other adults in household	Care for whom	Care recipient condition	Engagement with support services
16 (F)	Eldest	1	40 hours	None	Mother	Depression/ migraines	Yes
14 (F)	Youngest	2	35 hours	Adult brothers x 2	Mother	Cancer	Yes
9 (M)	Youngest	2	3.5 hours	Father/ husband	Mother	Lymphocytic gastritis/ depression	Yes
14 (F)	Youngest	1	5 hours	Father and mother	Brother	Cerebral palsy	Yes
10 (F)	Eldest	1	4 hours	None	Mother	Depression/ anxiety	Yes
9 (F)	Not applicable	0	10 hours	None	Mother	Epilepsy	Yes
17 (F)	Eldest	1 (not at home)	15-20 hours	None	Mother	Depression/ migraines/	Yes

Gender and age	Position in family	No. of other siblings	Time dedicated to caring weekly	Other adults in household	Care for whom	Care recipient condition	Engagement with support services
						fibromyalgia	
11 (M)	Youngest	2	30 hours	Mother	Brother	Epilepsy/learning difficulties	Yes
12 (M) & 16 (F)	Eldest	3	5-15 hours	Father/ husband	Mother	Depression/ mobility problems	Yes
12 (M) & 10 (F)	Not applicable	0	15-20 hours	Mother	Step father	Cancer	Yes
17 (M)	Eldest	2	35 hours	None	Mother	Diabetes/depression /fibromyalgia	Yes
9 (F)	Youngest	2 (not at home)	16 hours	Mother's partner	Mother	Fibromyalgia/ depression	Yes
12 (F)	Youngest	1 (not at home)	Less than 2 hours	Mother	Father	Physical disability due to stroke	No
6 (M)	Not applicable	0	Less than 1 hour	Mother	Father	Physical disability (army injury)	No
10 (M)	Not applicable	0	13 hours	Mother	Father	Depression	No
9 (F)	Eldest	2	10-15 hours	Father	Mother	ME	No
13 (M)	Youngest	2 (not at home)	5-15 hours	None	Mother	Cancer/arthritis	Yes
16 (M)	Not applicable	0	Less than 5 hours	None	Mother	Kidney dysfunction/ cancer	Yes
9 (M)	Not applicable	0	5-10 hours	None	Mother	Cancer	Yes
11 (F)	Eldest	2	25 hours	None	Mother	Borderline personality	Yes

Gender and age	Position in family	No. of other siblings	Time dedicated to caring weekly	Other adults in household	Care for whom	Care recipient condition	Engagement with support services
						disorder/depression	
15 (F)	Not applicable	0	5 hours	Father/ husband	Mother	Fibromyalgia/ arthritis	No
12 (F)	Not applicable	0	Less than 5 hours	None	Mother	MS	Yes

Note that in the sample participating in this research there was one very young carer aged 6 who provided less than one hour of care per week. They were included in the sample, despite the relatively low quantity of care provided, due to their young age and their not accessing support services.

Through a review of the data contained in Table 1, the following profile data provides context to the sections of this report which follow:

- Approximately half of the young carers involved in this research were younger carers (i.e. those aged 11 and under), one-quarter were young carers aged 12- 14 and one-quarter were older young carers (i.e. those aged 15-17). National census data on the profiles of young carers indicates that the average age is 13 (Office for National Statistics, 2011)

- A slightly higher proportion of girls (n 14) than boys (n 10) were represented in the study; gender differences were evenly spread across age groups. We know from the 2011 census that females are more likely than males to take on caring responsibilities[3] (Office for National Statistics, 2011), therefore we may expect to find some differences in respect of caring duties and needs in this research

- Half of the sample were lone parent families (n 11). The higher proportion of children and young people taking on caring responsibilities in lone parent families is a finding which has been identified in other research studies (Dearden and

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[3] In 2011, there were 177,918 young unpaid carers (5 to 17-years-old) in England and Wales. Of these, 54% were girls and 46% were boys (Office for National Statistics, 2011)

Becker, 2000). However, these same studies have also highlighted how having other adults in the household does not mean that a child will not take on caring responsibilities and that there are multiple factors that influence the onset, nature and extent of caring undertaken by children. Other factors include impacts of social exclusion, unidentified needs and lack of appropriate and effective support services (including family support)

- Mothers were the most common recipients of care in the sample which reflects the findings of previous studies (Aldridge and Becker, 1993; 1994; Dearden and Becker, 2000) that have shown mothers are more likely to receive informal care from their children and when mothers have illness/disability and care needs this can also transform family structure and circumstances. Ill/disabled mothers were more likely to be bringing up children in a lone parent household than were ill/disabled fathers within the sample for this research. Where the parent being cared for was the father there was another adult (a mother/wife) present to share the caring responsibility with the child or young person. This mirrors findings from earlier studies about the gendered nature of caring (see Aldridge and Becker, 1993; 1994)

- The most common reason that parents or siblings were cared for by children was when a physical health condition was present (n 10), however there were also a number of care recipients with mental health issues (n 8). In a small number of cases the cared-for individual had both a physical and mental health condition. Previous research (Aldridge and Becker, 2003) has indicated that referrals to young carer services of children who have a parent with a mental health condition have increased in recent years and that these children can experience a distinct set of challenges as children and as carers

- The recent census found that the majority of young carers (80.2%) in England and Wales provided between 1 and 19 hours of unpaid care per week (Office for National Statistics, 2011). This compares with almost three-quarters of the sample of children and young people involved in this research. A small number of young carers provided care for more than 20 hours a week though. Although this study involved a relatively small sample, the amount of time children spent caring appeared to be greater where a parent/sibling had a mental health condition or a debilitating condition such as cancer or fibromyalgia and where there was no other adult in the home

- Five young carers were identified as young carers not receiving formal support services.

2.2. Caring needs within the home

Most young carers were providing care for one parent except in one family where both parents were ill/disabled. As detailed in Table 1, within the sample there was a wide range of conditions that affected parents. The cared-for parents/siblings within our sample had received single or dual diagnoses of physical or mental health illnesses/disabilities, the nature and characteristics of which defined the initial care need. However in the interviews, approximately three quarters of families disclosed secondary, tertiary or comorbid physical and/or mental health issues, such as fibromyalgia or depression, which compounded their care needs and in some cases were not formally diagnosed. This was particularly marked in cases where the primary illness/disability significantly affected mental health, independence, coping and/or parenting ability. Given the prevalence of multiple health issues, many of which were either unsupported or resulted in unpredictable outcomes for those affected, young carers were not always able to understand their parent's/sibling's conditions, health and social care needs or how best to support and provide care in these contexts.

The health conditions of the cared-for parents had developed during adulthood either prior to or subsequent to the birth of their children. Where the condition was chronic or enduring but stable, families had had time to adapt to their situation and to make changes to their home and/or routines. In these situations young carers had a clearer understanding of their parent's condition and had more of a stable family routine.

However, for many young carers, the condition affecting their parent was not static but changed dependent on the management/treatment of the condition and/or the nature of the condition itself. In these households there was much less stability in family routines, and both parents and children had less opportunity to feel any sense of control over daily life as illustrated by the quote below. Similarly, in a small number of cases where the onset of a particular illness or disability had been more recent, such as in the last 12-24 months, families were often in the process of adaptation. In these cases young carers were developing an understanding of their parent's condition and what this meant in terms of the support their parent required.

> *"Unfortunately I don't have an illness that I can predict you know … I can't plan things."* (Parent of young carer aged 9)

The condition of cared-for parents/siblings sometimes resulted in increased or chronic pain, anxiety/depression, mobility difficulties and impairments to their cognitive functioning. In turn, these impacted on the cared-for parent's ability to work, to perform domestic tasks, to maintain personal and social relationships, and to engage in social

activities such as family outings and holidays. These all impacted on young carers who took on roles that helped support their parent/sibling in managing their condition or the impact of their condition. Whilst some parents and siblings were receiving health and social care to help alleviate these problems, others had not had appropriate support offered or identified, or were critical of the quality of the care provided.

The chronology or history of the illness/disability as well as the short and longer term prognosis, also emerged as factors influencing care needs and care-giving. Where chronic illnesses were managed less well, either by the parent or by support services, parental care needs were less stable/predictable. In these cases, support services lacked flexibility and were not always able to respond to care needs promptly so the burden of responding to care needs fell on the family, including children. Children who provided care in these contexts tended to be more anxious and vigilant, worrying about what might happen next and looking out for tell-tale signs that a parent may need their support to alleviate the symptoms of their condition. In cases where parents had deteriorating or terminal conditions (e.g. cancer or MS), children often lacked a detailed understanding of their parent's condition as parents were reluctant to discuss their prognosis.

> *"She's always asking me if I'm all right. There are times like I could just be sitting here and if I cough and she's in the kitchen or if I drop something on the floor she'll come running in thinking something's happened… "* (Parent of young carer aged 9)

Young carers of parents with mental health problems discussed the unpredictability of how the condition affected their parents and that their responsibilities changed from very minimal care to a high level of care, depending on the state of their parent's mental health at the time. This mirrors findings from previous research on children who live with and care for parents with serious mental health problems (Aldridge and Becker, 2003).

> *"When she's like she's proper ill and she just wants to sleep and stuff, then that's when I take over what she's supposed to do as well. I have to cook; I have to clean; I have to get her medications."* (Young carer aged 17)

Case study 1

Adama[4] is 11 years old. She lives with her mother and two younger siblings aged 1 and 5. Adama's mother, who suffers with borderline personality disorder and depression, is a victim of female genital mutilation, childhood sexual abuse and forced marriage.

> *"Until now I didn't understand it. I just know that I'm sick, mental, crazy… you have these strange behaviours in you and you don't know why and it's difficult... I want to be better because I don't want her to be doing all this [caring] for me."* (Mother)

Adama's mother has little contact with her children's fathers, she is unable to work and rarely leaves the house. She sometimes stays in bed all day and often feels suicidal and has self- harmed in the past. The family have received formal support from mental health, adult and child social services, young carers' projects and school staff which has enabled the family to function and stay together. However, due to the unpredictable nature of her mother's mental health and Adama's perception of expectations within the family that older children should help at home, Adama feels she carries a lot of responsibility for the whole family.

> *"I just help my whole family really. It's not only my mum I am helping… Sometimes I just get tired… tired of doing some stuff but I know I can't give up…"* (Adama)

On good days her mother is able to share more responsibility for the family and domestic tasks. However, when her mother is unable to provide care due to her condition Adama gives her baby brother his bottle at night and gets up very early to wake her siblings up, get them dressed and make the family breakfast before school. Adama often feels anxious about how her mother might cope during the day and what the home situation will be like when she returns from school. Immediate support is not always available but Adama will call her aunt or the mental health crisis team for help where the home situation becomes unmanageable.

> *"Sometimes she's very ill and I feel sorry for her… Sometimes when Mum is really, really stressed, I can't do anything… [when] she feels so bad she doesn't want my food… that upsets me and makes me cry."* (Adama)

Those parents with conditions that were more stable due to effective treatment or management (e.g. ME or epilepsy) were more able to retain their independence and

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[4] Note that while this case study (and those that follow later in this report) presents the actual story of individuals involved in this research we have replaced their name in order to maintain confidentiality

manage without regular social care or voluntary and community support groups, but this also risked over-reliance on other family members, including children.

Some care recipients were unable to parent in the ways that they would wish as a result of their illness/disability and/or lack of effective support services that recognised the needs of families, including children. The short-term or longer-term impact of conditions impacted on parents' abilities to communicate, engage and support their children in the ways that they would like or had done in the past. In some of the two-parent households, it was also apparent that the responsibilities of managing a house and supporting their partner reduced the amount of time and quality of the other parent's relationship with their children.

2.3. Talking about conditions and caring within families

Many parents struggled to discuss their diagnosis and the implications of their condition with their children, particularly with younger children and where conditions were more complex. In many cases parents initially explained to their child/children that they were not well and that they had particular symptoms (e.g. pains in the back) but did not go into detail about the actual diagnosis. For some this was because they did not want to worry their child/children, or because they did not think they would understand due to their age; for others it was because they themselves did not feel comfortable trying to explain the diagnosis.

> *"I don't think she really understands much about it because she still asks, like, why it happens, and obviously I don't actually know it myself."* (Parent of young carer aged 9)

> *"I was young, so they didn't want to tell me. I was feeling obviously sad and worried but shocked … you don't know what's going to happen or what could happen…"* (Young carer aged 12)

In the two cases where the condition affected a sibling rather than a parent, there was less discussion about their sibling's disability and care needs between the parent and their child who helped provide care. Some parents said that they did not think their child was "old enough" to understand the condition, while others did not fully understand the condition itself, especially in families where the illness/disability had been recently diagnosed. Children who were caring in families for ill/disabled siblings were often unable to understand the illness/disability and its implications for the whole family, including themselves.

Younger carers (i.e. those under 11) tended to have a less detailed and formal understanding of their parent's presenting illness/disability. This was in part due to being less informed by others (i.e. parents and professionals); from the parent's perspective there was a desire to protect their child from the detail of their condition and prognosis, a desire to maintain "normality", and/or a lack of confidence in the best way to broach the subject. However, all the children interviewed had some understanding of their parent's condition – or the symptoms of it – even if this was not medically informed, and many had taken on responsibilities that helped support their parent(s). For some younger carers, there was a clear desire to understand more about their parent's condition, particularly where the symptoms were unpredictable and therefore difficult for children to anticipate. Limited understanding resulted in greater worry for these children. However, it was also evident that some younger carers were cautious about requesting more information from parents in order to avoid any unnecessary upset (either for themselves or for their parent/sibling).

Young carers aged over 11 tended to be better informed about their parent's condition. This understanding typically developed with age through increasing familiarity with the condition, and discussions with their parents, with external agencies (e.g. school support) and/or as a result of their own research on the illness/disability.

> *"There was a lot of talking. I think they are both pretty aware now of you know, you've both read up on it… and they both know what I am going through."* (Parent of young carer aged 15)

In a number of cases, parents recognised over time that having two-way in-depth conversations about the health issues and care needs in the family was the best approach, ensuring children felt well informed and emotionally supported. In these cases parents had a better understanding of their condition and felt more comfortable discussing aspects of their diagnosis and prognosis. Interviewers observed a strong and open relationship between these parents and their children; young carers demonstrated an understanding of their parent's condition and presented themselves as more confident and reassured.

> *"I do talk to my Mum about feelings because sometimes I have worries that I just want to get out… If I keep it in my head I just worry about them all the time. But then I just get them out it makes me feel a lot better about myself."* (Young carer aged 9)

2.4. The nature of young carers' responsibilities

The responsibilities of the young carers varied according to the illness/disability and the consequent care needs of parents/siblings, and the availability of other sources of support (both formal and informal). Most children and their parents found it difficult to estimate the average amount of time young carers spent on caring tasks on a weekly basis. It varied from day to day and week to week, according to changing needs and circumstances within the household. When caring activities were discussed and broken down in detail, it was apparent that most young carers were undertaking caring tasks for between 5 and 15 hours a week[5]. However, it is important to note that children found it difficult to recall exactly how long they spent on tasks.

Older young carers tended to take on greater responsibilities – and for more hours per week - than younger carers or those young carers not receiving formal support services, although there were exceptions depending on the family structure and circumstances. However, it was evident that practical and physical tasks were considered as "caring" type responsibilities, whilst other activities were less likely to be directly discussed as caring by families and children. These included activities such as keeping parents or siblings company, providing emotional support, overseeing younger siblings and going out with the cared-for parent or sibling (as some would not go out alone).

> '… little things that I do that cheer them up, whether it's a big cuddle… a small back rub, a cup of coffee..." (Young carer aged 10)

> "He's always at my bedroom door two or three times in the night just to check on me. Are you all right, Mum? " (Parent of young carer aged 17)

Many parents tried to limit the responsibilities that young carers took on to what they perceived to be appropriate, reasonable or what other children the same age might be expected to do, particularly in two parent families and those with access to informal and/or formal support. Some young carers, particularly older ones, perceived their responsibilities as relatively 'normal' and not out of the ordinary for their age. However, they usually acknowledged they would do more around the house than did their peers.

> "The majority of people my age they don't really have a mum with a disability, so they don't really do that many jobs (around the house)…" (Young carer aged 12)

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[5] Calculations were performed by the research team during analysis rather than being undertaken during the interview

"If she didn't have a disability then…a lot of the stuff I probably wouldn't have been doing because I wouldn't have needed to because she would have been capable of doing it. But as I got older I probably would have helped out [more], but not at that sort of age [began caring at 7 years old] I don't think I would have." (Young carer aged 16)

A minority of the young carers undertook tasks and responsibilities that were recognised by their parents as being over and above what would be expected for their age in a household where a parent did not have an illness/disability. These responsibilities included providing personal care, taking responsibility for caring for younger siblings (including children aged under 11 years old), and taking on household tasks such as finances and budgeting.

"I don't only help my mum; I help my brother and my sister as well because they're obviously little, so I have to take my brother his bottle at night…" (Young carer aged 11)

Younger carers undertook simpler tasks, such as keeping parents/siblings company and making drinks, whilst older young carers' tasks were more often more complex (e.g. providing emotional support, food preparation and helping siblings prepare for school and to complete homework). The structured assessment tool, MACA-YC18, was used to explore caring tasks and responsibilities in more depth. Below we outline the range of responsibilities that young carers undertook within the home. These have been arranged to illustrate the most common tasks first, but also to detail the more complex tasks that young carers took on, often as they got older:

- Domestic chores - making drinks, fetching/carrying items, tidying/cleaning, lifting, helping prepare food, helping to do laundry, helping with the shopping (e.g. carrying bags), basic cooking

- Emotional/psychological support – spending time together keeping parent/sibling company, checking up on parent/sibling, offering reassurance, being there to allow parent/sibling to share feelings, providing cuddles and hugs to support parent/sibling

- Caring for younger siblings – playing and reading together, overseeing feeding/bathing/homework, helping siblings to get dressed or get ready for bed, walking siblings to/from school

- Physical contact to alleviate pain/tension – providing therapeutic rubs and massages in order to ease physical symptoms of parent/sibling illness/disability

- Assistance with mobility – observing and spending time with the parent/sibling in order to offer support where needed, physically helping parent or sibling to get around the house or outside

- Help with medication – reminding/checking that medication had been taken, helping administer medication

- Financial responsibilities – undertaking visits to local shops alone, completing online shopping, helping to complete budgeting activities for the household

"If we're going out or something on the bus you have to, like, constantly remind him about the time, or something about money that he doesn't understand or forgets so you have to keep on repeating it." (Young carer aged 14)

- Personal care - help dressing or washing, getting in/out of bath/shower, toileting, changing stoma bag or cleaning stoma area

"Some of the time, I get him his clothes, take his clothes out and push them in the washer. I take his shoes off sometimes…" (Young carer aged 12)

2.5. Factors influencing the roles/responsibilities of young carers

A wide variety of factors influenced the roles and responsibilities of young carers, from the nature of the parental/sibling condition, as discussed in Chapter 2.3, to the family dynamic and structure.

Children's caring responsibilities were less onerous when caring was shared within the family and, for some, beyond the immediate family, including relatives (grandparents, aunts, uncles, cousins and adult siblings), neighbours and friends of their parent(s) or, for a few older young carers, their own friends. Children had a higher degree of responsibility within lone parent families and those where children had no siblings (or very young siblings) compared to those in families where another adult or sibling were present. Similarly, where one parent worked full-time this led to increased caring responsibilities for some children. In a two-parent household, the working parent tended to take on more responsibility during evenings and weekends, whilst young carers were generally more involved in the mornings, immediately after school and during school holidays. Holidays were particularly challenging for most young carers due to an increase

in their caring responsibilities at home and the lack of opportunity to take breaks to engage in other activities both inside and outside the home.

Children's caring responsibilities were also less onerous when health and social care professionals were aware of the condition affecting a parent/sibling, and of children's caring responsibilities. Where support services were involved and providing adequate and appropriate support to ill/disabled parents/siblings and to families, children's responsibilities (and those of other family members) were reduced. The range of interventions offered to families included:

- Health/medical care e.g. GP, clinic and hospital consultations, including occupational therapy and physiotherapy

- Physical aids and adaptations to the home e.g. rails, stools, walking sticks, wheel chairs and wet rooms

- General assistance and social care support with everyday living, such as personal care, domestic tasks, mobility, transport, meeting some childcare needs and one-to-one personalised care support

- Psychological support, including counselling, therapy and support groups

Family support not only helped the cared-for person to become less reliant on the young carer and/or other family members, but also freed up more of the young carer's time to engage in their own activities and interests, including social activities and school work.

However, not all parents felt comfortable disclosing their condition/circumstances to outside support agencies for reasons ranging from fear of stigmatisation to being seen as a parent who was failing in their parental role, leading to concerns about undertaking a parental capacity assessment (barriers and facilitators to accessing support, and experiences of support, are discussed in detail in Chapter 4).

> *"Basically we've had to muddle through by ourselves really … I would say not accessing the practical stuff and support networks out there was his choice"* (Parent of young carer aged 12)

> *"It was like as if you were going to be labelled as disabled and I didn't want that … We've worked out our own system…. I try to retain that normality as much as possible….I didn't want to be pigeonholed."* (Parent of young carer aged 12)

Age was a significant variable in the extent to which children took on caring responsibilities, and parents' expectations of support from their children. For younger children (i.e. those aged 5-11), the cared-for parent or other family members tried to limit

the extent of caring children provided. This was more challenging for lone parents, only children or where a young carer was the oldest child in the family.

> *"I don't get him to do much, to be honest. He's a bit spoilt. He's my little man."*
> (Parent of young carer aged 6)

For older children, there were increased demands placed on them by parents to provide informal care because there was no one else available to provide care, and/or actively took on more responsibility as they became more mature and aware of the support needs of their parent/sibling. These responsibilities could conflict with the various social commitments and emotional challenges of adolescence, educational transitions and pressures (homework and exams), and planning for their own future. Some older young carers talked about actively trying to limit their caring role in order to live their own life more fully. This was something that was more achievable in two-parent households, or where young people were able to share care with other siblings and relatives, or where appropriate and effective health and social care services were available. Where young carers were also responsible for providing care to younger siblings, reducing care responsibilities was more challenging. In these cases children reported feeling accountable for the welfare and care of siblings in the absence of appropriate support from adults within the household or support services

In addition to age, the nature and extent of children's caring responsibilities were influenced to some extent by parents' gender assumptions. Girls were generally seen – by parents - to be more "natural" carers, but many boys had developed practical and emotional caring skills that helped meet the needs of parents and siblings. In some families, the more physical or practical tasks were managed by the boys and more personal care or emotional support by girls, but in other cases, due to the age or absence of other children, both male and female young carers supported parents with a range of caring tasks/duties. As has been evidenced in previous research (e.g. Becker et al, 1998; Aldridge and Becker, 2003), providing personal, nursing-type care was seen by parents to be the most challenging or sensitive form of care provided by children, although not necessarily by young carers themselves. Seven young carers were involved in providing this type of care, largely for parents who had a physical disability or mental illness which resulted in physical symptoms.

> *"She [my daughter] said a 12 year old [boy] should not be putting mum's pants on."*
> (Parent of young carers aged 11, 12 and 16)

> *"The girls used to help me sort of dress and help me with my stoma bag and help me in and out of the bath and that, but obviously I've* [now] *got a carer to do stuff like that for me."* (Parent of young carer aged 17)

The role of young carers was affected by a range of other systemic and family issues that could compound the impact of the condition both for the parent affected and for their children. These are detailed below and have a common effect of increasing instability within the family home.

One frequent issue affecting families was a reduced household income if one or both parents were unable to work due to the illness/disability or caring responsibilities. This led to a reliance on welfare benefits and a reduced disposable income, in turn affecting the quality of living conditions, the ability to purchase healthy food, and opportunities for taking part in affordable social activities including family holidays. In one case the family had rented out rooms in their home in order to generate additional income.

> *"I think the biggest shock was the financial shock where, you know, one minute you had a very good wage and next minute … there was a while where we had nothing …"* (Parent of young carer aged 12)

There were examples of past and ongoing substance misuse among parents, and past domestic abuse of the cared-for parent and/or children within the home. These issues often preceded the condition that affected parents and continued once a condition was diagnosed.

Family breakdown was fairly commonplace – half of the families in the sample were lone parent families. Some of the reasons for family breakdowns were parents separating from one another, disagreements occurring with relatives, and in some cases, a parent being incarcerated. In the majority of cases family break-downs had happened prior to the onset of illness/disability, however some families explicitly discussed this as a result of the impact of the illness/disability. Allied to the issues above, there were also young carers within our sample who either themselves or their siblings had previously experienced a care order (either going into foster care or a children's home), shared care arrangements or had left home while still under the age of 16.

Social and/or geographic isolation was also experienced by a number of families who lived in rural areas. Where a family was geographically isolated this affected their ability to access formal support services and informal support networks. This subsequently increased demands on family members, including children, to provide care. Social isolation was relatively common within the sample of families in this research, often starting at the onset of an illness/disability and increasing with time. This was particularly the case in lone-parent families.

> *"I've got no support here and with her [Young Carer] being on her own …*
> *Obviously if I was in town I've got my mum, my brother and my best friend, literally*

five minutes away. So that would take a lot more pressure off her … we're both finding it difficult, anyway." (Parent of young carer aged 9)

The comorbidity of health issues and the multiplicity of social issues that affected families in our sample – as well as the family structure and the availability of other family members to provide care - can be seen as having a direct impact on the nature and extent of young carers' roles and responsibilities within the home. Where parents were less able to support themselves and/or had less access to support that helped promote resilience and address presenting needs, children were drawn into a caring role.

2.6. Summary of the chapter

In summary, the sample of young carers involved in this research is not dissimilar to that involved in other research studies on young carers. As has been the case with previous research, the young carers in this study were more likely to care for a mother than a father or sibling, and lone parent families were over-represented in the sample compared to the general population.

While cared-for parents/siblings all had single or dual diagnoses of physical or mental health illnesses/disabilities, these were often accompanied by other physical and/or mental health issues that were not always formally diagnosed. This presented a considerable challenge for young carers in understanding the support needs of their parent/sibling. Similarly, conditions which were relatively new (i.e. in the last 12-24 months), or those which fluctuated or progressively worsened over time, resulted in less stability in family routines and less opportunity for children to become familiar with the condition, leading to anxiety. Conditions invariably had an impact on the cared-for parent's ability to work, undertake domestic tasks and to maintain social relationships, all of which influenced the family dynamic and therefore the young carer.

The unpredictability of some mental health conditions meant that the nature and extent of children's caring responsibilities varied considerably, and this lack of predictability also meant that support services were not always available when needed. Those young carers who had a parent with a mental health condition indicated that a change for the worse in the condition prompted anxiety and increased their caring responsibilities. Conversely, where conditions were more stable due to effective treatment or management, parents had a higher degree of independence and often the caring responsibilities that were undertaken by their children were lessened.

Parents sometimes struggled to discuss their conditions with their children, particularly where conditions were complex or terminal, or where the child was young. While they

talked to their children about the symptoms, parents often felt uncomfortable explaining the actual diagnosis. Young carers who cared for a sibling often had limited understanding of their sibling's condition and, while familiar with their care needs, this caused anxiety where conditions became worse. With increased age often came a better understanding among children of the condition affecting their loved ones, gained through familiarity with the condition and through conversation with parents or professionals from support services. However, there was a clear desire among young carers of all ages to better understand the condition of the cared-for person.

The responsibilities of young carers varied enormously depending on the family structure, the nature of the condition and on their age and gender. Older young carers, and those in lone parent households, tended to take on greater caring responsibilities and felt more responsible for providing support than did younger carers or young carers not receiving formal support services whose parents actively tried to limit the amount of caring undertaken. This ranged from practical support (e.g. household chores, shopping, caring for siblings) and emotional support (e.g. keeping parents company) to more therapeutic or personal care (e.g. helping parents wash themselves, providing massages, administering medication). The gender divide was not significant but, in some families, girls were providing more of the emotional support and personal care, whereas boys undertook more practical support around the home. In most cases young carers were happy to provide caring support however there were some responsibilities, such as helping to manage household finances, where they were clearly less comfortable due to lack of experience.

Children's caring responsibilities often increased during weekends and holidays when children spent more time at home. Parents recognised this and talked about the need for children to take regular breaks from caring and for them to engage in other activities both inside and outside the home.

3. Experiences and impact of caring on children and families

This chapter will explore young carers' experiences of providing care and the impact of caring on children and families from both the young carers' and the parents' perspectives. It will examine the nature of care provided in more detail, as well as the positive and negative impacts on children of having to provide care for a loved one at home.

3.1. Views and impacts of caring

The impact of caring on young carers' lives was something that both young carers and their parent(s) found quite difficult to discuss in depth. It was typically an emotive subject and not something that either parents or the young carer themselves explicitly discussed with one another.

When asked to talk about the experience of caring, young carers tended to focus on a range of mainly positive emotional and psychological impacts, such as pride, self-worth and feeling closer to their cared-for parent/sibling. Many older young carers felt that caring had enabled them to develop a range of practical and useful life skills such as cleaning, cooking and managing finances, as well as an ability to cope with difficult situations and to better understand people. For these young carers, caring had given them an increased sense of independence, competency and maturity.

> *"I see it in a positive way because… when it comes to moving out and having my own life, I'm going to be used to it already."* (Young carer aged 16)

> *"I think I became a better person because I've had to look after her more… I've had to be more patient with her… I've learnt to put her first … a few years ago I probably would have killed her by now. "* (Young carer aged 17)

Views from young carers about the more negative aspects of caring related primarily to having a loved one with an illness/disability, and the uncertainty and worry this caused about their family member's future health and wellbeing. They also mentioned having less time to spend together as a family doing things that were unrelated to caring. There was a degree of reluctance, among both young carers and their parents, to articulate some of the more negative impacts of caring. When discussing their parents' illness or disability, young carers did not want to be seen to be putting their thoughts and feelings first.

"That's like the caring side of it, the helping out makes me feel good but for the other stuff going on I do feel down in myself anyway..." (Young Carer aged 14)

For some young carers, the act of caring had become normalised; it was part of their routine and their responsibility. As such, many young carers (particularly younger carers) reported that caring had a limited impact on their everyday life and was "just what I do".

"It doesn't affect me in any way, really like emotionally. I am just used to it..." (Young carer aged 16)

"I don't really see it as a chore, I just see it as something I do… my Mum's fibromyalgia doesn't really affect me that much." (Young carer aged 15)

Through more detailed discussion with parents, children and young people it was possible to identify both positive and negative impacts of caring across a number of areas as illustrated in Case Study 2. These areas included: family dynamics and relationships; social activities and interests; health and wellbeing; education; life planning; and financial management.

Case Study 2

Katie is 9 years old and has not disclosed her caring to any statutory agencies or local organisations. She is currently not receiving any formal support services. She lives with her mother, step-father and two younger siblings aged 2 and 6. Her mother has had Chronic Fatigue Syndrome/ME since the birth of her last child as well as a heart condition which requires regular check-ups and surgery. The severity of the impact of her condition/s varies from day to day. Both parents currently work full time, although Katie's mother has had a significant amount of time off work due to her illnesses.

Katie has also experienced other challenges in life which have included her parents' divorce, her biological father leaving the UK, the recent death of her grandmother and a period of hospitalisation herself.

Physical aids enable her mother to be as independent as possible, but Katie cannot go to after school activities or see her friends when her mother is feeling at her worst because she is needed to help out at home.

"Unfortunately I don't have an illness that I can predict you know… It's a big balancing act really… I do lean on her [Katie] a great deal because from day to day we don't know how I'm going to feel… I hate to think of it like that but I do find myself saying… "can you just?"… she's my go-to-girl!" (Parent)

At such times Katie helps more with household tasks and overseeing her younger sisters, whilst her step-father takes the main share of responsibilities during mornings, evenings and weekends. Katie's mother feels guilty about the responsibilities being placed on her daughter and does her best to limit how much she relies on Katie. Katie's mother would

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like home help to ease the burden of care for Katie, but cannot afford to pay for this type of support and is not aware of other support she could access to help.

> *"I think she's very sensitive and that has its positives… she's very caring with others … I worry about her anxiety levels, she does worry about me a lot … she goes to school and she'll say I don't want to leave you … She worries she's going to get the same thing, that is always playing on her mind…"* (Parent)

Katie feels proud that she can help care for her mother and sisters, but feels a great deal of responsibility for ensuring that her family are looked after.

> *"I like being helpful… I like most of the jobs I do… I like to help mum… and I feel I should do the things I don't like… I have a lot of responsibility because I have to make sure that my younger sisters are happy and don't do anything silly, just be safe, so nothing hurts them or anything… I don't want to stop caring for my mum because she's a lot more important than anything else."* (Katie)

Katie struggles to concentrate at school because she worries about her mother. She would appreciate more time to herself at home to do her homework and spend time on hobbies and other activities. However, sharing her feelings with her parents and favourite teacher has helped Katie cope with her anxieties about her mother.

"… sometimes I'm not that focused … I do get distracted a lot… I would like more time for myself … and not to miss some of my activities … If I keep it (feelings) in my head I just worry about them all the time. But then I just get them out it makes me feel a lot better about myself." (Katie)

Family dynamics and relationships

Both young carers and their parents discussed the impact of children's caring roles on family dynamics and relationships. Four main effects were identified. First, it was noted by most parents that *closer relationships and a stronger family bond* had developed as a result of children providing care.

> *"In a way it's brought us all together. We are closer and we know what to do. Like, you feel more involved and cared-for. Like, because you know things can hit you, like that."* (Young carer aged 12)

Some young carers felt they were naturally close to their parents and that caring had not brought them any closer. A few young carers, particularly children with a parent that had a mental health condition, felt a greater distance had developed due to the illness. This is supported by findings from Aldridge and Becker's (2003) study of children living with and caring for parents with serious mental health problems.

Second, the growth of a *mutually supportive relationship* whereby the young carer and parent(s) felt that "we are all in this together". This was particularly marked in families where there were higher levels of openness in discussing needs, feelings and sharing mutual experiences. For younger carers, and young carers not receiving formal support services, 'supportive' meant more of an emotionally supportive relationship than practically or physically supportive. It was evident that some young carers, particularly younger carers, were in part meeting their own needs for reassurance by checking on the cared-for person's wellbeing and spending time with them.

Third, some young carers had become more *independent and self-sufficient*, taking on a level of responsibility over and above what might be expected at their age. This was more common in lone parent families and/or where young carers had brothers or sisters and their role was perceived by parents (and the young carer) as critical to the overall running of the household. Parents often described this as the young carer becoming more mature and responsible within the family context.

> *"She's become less dependent on me. I think in her eyes the roles have turned around. I think she thinks she's the mum now, to be honest but I think that's just in her character because she's always been independent. It's always just been me and her, so I think she sees I've always been strong and independent and she kind of takes that on as well…"* (Parent of young carer aged 9)

Fourth, increased *tension and strain within the family dynamic* was acknowledged by some young carers and parents, particularly where families were struggling to manage, and perceived themselves as having insufficient external health and social care support. For some families this tension within the family was solely the consequence of the parent's/sibling's condition or the side effects of medication. In these cases the tension was related to difficulties in coping on a practical and/or emotional level, plus the lack of opportunity to spend quality time together (or apart).

> *"It's like any normal family. You have arguments and you sort of say things you don't mean sometimes but they're your family. You've only got one. You can't really jump ship when things go wrong."* (Sibling of young carer aged 14)

Social activities and interests

Many young carers, particularly the older ones, felt that their caring responsibilities limited their opportunities and ability to engage in an active social life or pursue their own interests outside the home. It was common for young carers to feel like they did not have enough free time available and often had to cancel time planned for spending with

friends, at clubs or on leisure activities because they felt that they had to be at home to provide care and/or because they were worried about their parents/siblings.

Feelings of guilt were mentioned by young carers when recalling leaving the cared-for person at home to go out with friends or take part in activities. It was evident that even in their free time, young carers often felt unable to fully relax and enjoy themselves. Some said that they felt anxious and concerned about the possibility that something might happen to the cared-for person in their absence. This was a significant issue in lone parent families, particularly where younger siblings were present and the oldest child was the main carer within the household.

> *"… even when I'm in a football match I'll always worry about my mum… I'd rather be with her knowing that she's alright than be with my friends."* (Young carer aged 17)

Some young carers, particularly older young carers, explicitly discussed wanting more time for themselves to spend developing their own interests outside of caring. This desire for more free time was less evident among the youngest carers, possibly because they were more accepting of their caring role and home situation, and/or because parents typically tried to support younger carers to engage in social activities, many of which were school based and extended the school day by 30-60 minutes.

> *"I don't mind helping but I would like more time for myself and not to miss some of my activities."* (Young carer aged 9)

> *"Since my mum can't really do anything with me, my weekends are pretty boring. It's really frustrating when I can't do anything at the weekend ..."* (Young carer aged 13)

Young carers in families where caring responsibilities were shared among other siblings or adults, or where there was sufficient external support, had more opportunities to engage in social activities. Supporting children in their activities outside the home, was a way for some parents to compensate their children for caring.

Health and wellbeing

Young carers did not directly link caring responsibilities to any issues or concerns about their own physical or mental health. However, they did talk about the impact on their psychological health and well-being, which is discussed below. The structured assessment tool, PANOC-YC20, was used to help explore the positive and negative emotional impacts of caring in more detail.

All young carers felt proud of their caring role and the contribution they made at home. They also felt that their parent(s) were proud of them which helped to boost their feelings of self-esteem and self-worth, particularly amongst younger carers. Caring was felt to have a range of positive impacts, including developing good social, emotional and listening skills, empathy and understanding of others, being a good friend, maturity, tolerance and the ability to manage difficult situations. Among young carers not receiving formal support services, these same benefits were evident although less marked, possibly because their caring responsibilities were comparatively less than other young carers within the sample.

> *"I can tell if I'm doing a good job by their facial expression… if they're smiling, if they're doing things with me… that's when I know I'm doing a good job."* (Young carer aged 10)

> *"I just feel proud because I'm doing something good for my mum, and because my mum has always been there for me I want to do the same for her, that's why."* (Young carer aged 6)

Both parents and young carers discussed that a caring role had a negative impact on children's emotional wellbeing, in particular being associated with tiredness, stress, depression and anxiety – all impacts that have been documented in other research (e.g. Dearden and Becker, 2004; Frank, 1995). In some cases these impacts were a result of the emotional strain of having an ill or disabled parent (or sibling), particularly where a condition was not managed effectively through appropriate health services. In other situations the stress or tiredness among young carers was linked to their physical caring responsibilities, and balancing this with other responsibilities.

> *"Sometimes I just get tired… tired of doing some of the stuff but I know I can't give up."* (Young carer aged 11)

> *"I get stressed, like, proper easily and worked up about myself. I can feel that sometimes when you hear, like, Dad moaning and saying that he's got so much pain, you just, like, want to grab your hair, like, pull it all out and you're just like oh … make it stop, make it stop."* (Young carer aged 12)

Isolation was not mentioned frequently but young carers who were an only child or in lone parent families reported feeling lonely more often than did young carers in other family structures.

Some young carers, particularly older young carers, described feelings of anger and frustration, but these were rarely expressed openly within families. In these cases, young carers admitted actively trying to manage these feelings by hiding these from their family,

particularly in front of the cared-for person. Some male young carers had anger or behavioural issues which surfaced at home and within school, and were in part attributed to frustrations resulting from their caring role.

> *"You know when you feel like angry and you don't know why, that sort of thing because I am angry at how this has happened, why has it happened… Sometimes I hit the wall that hard that I do hurt myself."* (Young carer aged 12)

> *"The fact I have to do things constantly, not just one thing every now and then. It's just… it's so constant it gets annoying... I don't get angry about it, just a bit fussed."* (Young carer aged 13)

Some young carers were receiving therapeutic support in order to manage anger, behaviour, anxiety or eating disorders such as anorexia and bulimia. These were not discussed as directly related to their caring responsibility and would therefore require further research to understand any potential causal linkages. Others had developed their own coping strategies to manage or deal with their emotions, including a worry book, writing a diary or pursuing leisure interests/activities such as art and football that helped them to manage stress. Parents and children sometimes watched TV or films together, while for younger children simply finding time to draw or play helped them relax.

> *"…if she's got a worry about me she'll write it down and then they'll talk about it and I don't know anything about it because that's their time.* " (Parent of young carer aged 13)

Education

As with many children and young people, experiences of school varied between individuals, with some reporting feeling motivated and enjoying their education while others felt less positive. Caring responsibilities, as discussed below, had an impact on the academic engagement and performance of some of the young carers in the study. Where less impact was reported, this tended to be in families where there was sufficient external support was being received or where parents actively tried to minimise their children's caring responsibilities to reduce the impact of caring on their education.

Many young carers discussed the challenges involved in balancing caring and school work. These included managing feelings of preoccupation, experiencing problems concentrating in class, having limited time to finish homework at home and, missing deadlines and school days to provide care at home. They also reported not wanting to leave the cared-for person, particularly if they remained home alone while the young carer was at school. Some parents acknowledged the difficulties their children faced

juggling school and caring responsibilities, and expressed concerns about it impacting their wellbeing.

> *"He found it hard. Helping out at home and looking after me, he found it hard going* [to] *school. When we had the breakup as well, he didn't want to go to school because he didn't want to leave me."* (Parent of young carer aged 17)

> *"She used to say that she wants to kill herself… She used to say when you go out I'm going to do it. I used to have to stay in with her and sometimes I didn't go to school actually." (*Young carer aged 17)

Young carers experienced more problems in balancing school and their caring responsibilities where school staff were not aware of the young person's situation. This was more common amongst older young carers in secondary school who were reluctant to be singled out and seen as different or requiring special attention, and therefore had not disclosed caring with school staff themselves. Some young carers had learned to negotiate and plan their education around caring through various coping strategies, including doing their homework at lunch or break times so they had less to do at home. However, examination periods – particularly at GCSE level - were highlighted as a particularly stressful time for many young carers because of the need to balance the time needed for revision and the general stress of exams with their caring responsibilities and the pressures accompanying these.

> *"I was stressed because I had my GCSE's as well. I wasn't doing very well and she was taking up loads of my time at home, so I couldn't revise… I was like, because I'm revising, there was just too much pressure."* (Young carer aged 17)

Some parents expressed concerns about their child transitioning to secondary school or changing schools when moving house, as their children were settled and benefiting from the support currently available within the school. Some young carers, particularly those in secondary school, felt that behaving well at school and achieving academically made their parent(s) happy. In a number of cases young carers saw this as a way of reducing parental concern about the impact of caring responsibilities on them. Where the young person was successful in doing this it helped their self-esteem and well-being, however for others, balancing caring and success at school was a significant challenge.

> *"I used to go to school because that would make her happy if I went… Plus if I went… she wasn't going to get in more trouble*" (Young carer aged 17)

> *"My role is just being good and being safe and being quiet and being in education."* (Young carer aged 9)

Bullying was being, or had been, experienced by three young carers, and these children attributed this at least in part to their caring role and family situation. Where bullying was experienced, this made it more challenging to engage and succeed in school, and to develop and maintain friendships with peers.

> *"I am always working on my own... I am like the odd one in my class… Because of caring I feel I am unusual… I ask if I am allowed to join [their groups] they say no."* (Young carer aged 12)

Life planning

The age of the young carer had a strong influence on the extent to which they had thought about careers and life-goals, and the degree of importance placed on future life planning. Younger carers who were still at primary school often had career aspirations that changed according to developing interests. Older young carers, particularly in post-16 education, were starting to think more seriously about life beyond compulsory education, including further and higher education and training, as well as future careers. For these young people, key concerns related to maintaining a good level of engagement and achievement at school to provide them with a strong foundation from which to make future decisions. Related to this, many young carers talked about the importance of securing a good job/career when they left school to help improve the financial resilience of their family, and potentially to contribute financially towards the cost of meeting care needs. This was particularly the case in lone parent families or where there were younger siblings present in the household.

Two of the older young carers involved in this research who were in further education, expressed concerns about funding their education or training due to family financial circumstances. In these circumstances one family had taken out a loan to pay for a course, while in the other family there was stronger pressure on the young person to get a part-time job in order to fund further learning.

> *"We had to get loans so I could go to college because she couldn't afford for me to go there."* (Young carer aged 17)

> *"At the minute I want him to get off his arse and look for a job as well, a part-time job… If he wants to go and do further education, that's fine by me, but then he's got to have a part-time job to support him as well."* (Parent of young carer aged 17)

The majority of young carers expressed concerns about the cared-for person and fulfilling caring responsibilities when thinking about the future. The thought of leaving home was a cause for concern, particularly among older young carers and especially among those in

lone parent families or when they were the only child at home. While independent living was further off for younger carers this did not stop them being aware of difficult future decisions being influenced by their caring responsibilities. Young carers who had comparatively fewer caring responsibilities were still keenly aware the situation could change, with more possibly expected of them in the future.

Young carers sometimes felt that caring was a potential barrier to fulfilling future hopes and plans. This was typically the case where young carers were already experiencing challenges balancing school with caring responsibilities because they were not adequately supported as children in need and as carers. Young carers often reflected on the practicalities that would need to be addressed were they not undertaking their caring responsibilities: how would the cared-for person and/or family cope if they reduced their caring role, and who would fill the gap that was left? And importantly, how would they and the cared-for person feel about this change? This was of more concern to young carers in lone parent families and to those who had received limited or inadequate external support to meet the needs of the cared-for individual. On the other hand, where other formal and informal supporters and networks existed, this helped to moderate concerns held by young carers (this issue is discussed further in Chapter 4).

> *"I've already started thinking about what I want to be, but I don't know if I would want to go in case something happened while I'm away."* (Young carer aged 12)

> *"I want to move to London when I'm older but I don't want to leave my mum because she'd be all on her own and she doesn't want to be… I'll stay but I don't want to stay."* (Young carer aged 17)

Parents discussed the importance of support in helping their children with future planning and life transitions, particularly the transitions between primary, secondary and further education and into employment. Many of the parents reported that, while they did not have firm plans for how they would manage without the support of their child or children, they were keen not to hold their children back. Parents with partners, other children in the household and/or external support were generally less apprehensive about the future - both for themselves and their children. Parents of older young carers had already reflected on the possibilities of managing when their child was studying or working and therefore less available to perform a caring role.

> *"I want them to live their own life. I don't want them to feel that, oh, they've got to stay at home or they've got to look after me."* (Parent of young carer aged 17)

Financial management

Within our sample of families, most parents managed family finances alone without any involvement from their children. The exception to this were lone parent families where the cared-for person struggled with mental health or cognitive functioning – in these cases young carers had become involved with finances. This ranged from handling family money when shopping, to budgeting and management of household bills. For some young carers this responsibility was undertaken despite them feeling that they had limited knowledge and ability to undertake this role.

> *"I have to proper think about it (money) and she don't help as well because she says where's this money gone? I don't know. It's like, well you must know because you've spent it and then I have to go through everything… make sure she's not spending all her money…"* (Young carer aged 17)

> *"No-one tells you, you just have to kind of do it, don't you? You don't go to school and then they tell you how to do budgeting, you just have to try your best. No-one's told me how to use an iron so I can't use it. No-one taught me."* (Young carer aged 17)

As detailed in Chapter 2, for some families the onset of illness/disability affected a parent's ability to engage in paid work or receive appropriate and sufficient welfare support – for example, reduced income, subsistence on benefits and reduced working hours. Younger carers were less aware of financial issues, but many were conscious of some of the impacts on family lifestyles (including lack of opportunities for family activities and holidays) though these were also influenced by the wider impact of the cared-for person's condition (e.g. a lack of confidence, energy or mobility). Older young carers were more conscious of any financial difficulties within the family as they were typically more involved in family discussions on the issue.

> *"She gets frustrated that she can't do the family things, like, going on holiday, because we haven't, as a family, been away since he's had his stroke. She is missing out on certain things but unfortunately circumstances dictate, you know, we don't have the money that we did when she was younger."* (Parent of young carer aged 12)

3.2. Perceptions of the 'young carer' identity

> *"He's my young carer…"* (Parent of young carer aged 17)

For those young carers who were accessing local support services, the term 'young carer' was recognised to be a familiar term and one which they acknowledged accurately described part of their role within the family home. However, the term invoked mixed

feelings among young people. While many young carers felt proud of their role, responsibilities and abilities, and the fact that this was positively recognised by people outside of the family unit, some young carers had also experienced more negative reactions to their role. In this respect there was recognition, particularly among older young people, that the term 'young carer' could carry with it stigma (by association).

> *"Because like most people are quite judgmental and most of the people that I go to school with if I told them they'd say that they understood, but then they'd talk about it behind my back and use it like as an insult."* (Attendee at Young Carers' Support Project)

Older young carers were more sensitive about the use of the term than younger carers and, consequently, many had avoided disclosing their caring role at secondary school for fear of being singled out as being different and treated differently by pupils and staff alike. This related to possible teasing, name calling or bullying by other pupils, or feeling forced to discuss their feelings by school staff. Many younger carers had experienced good support from school staff, but some had felt picked on by their peers because they were perceived as different to the other children and received additional support and flexibility at school because of their caring role. Some young carers were cautious about who they choice to disclose their caring role to beyond their immediate friendship group.

> *"People won't like tell people like they're a young carer because they'll be over sympathetic like they'll put loads and loads of pressure on you by making you explain everything and then it mucks your emotions up and you'd just end up crying".* (Attendee at Young Carers' Projects)

Young carers not receiving formal support services did not self-identify as 'young carers'. Some parents, particularly of young carers not receiving formal support services, were cautious about the term being applied to their children because they felt it may stigmatise them. They were also concerned it might add to their burden, in addition to labelling and reflecting negatively on the cared-for person. This related to some of the concerns raised by parents about their children receiving support from dedicated young carers' projects since this would formalise and label their child as a young carer.

> *"I don't want to label her as a young carer, as such. I don't want her to carry that with her at this moment in time, because I think, you know, being 12 years old is stressful enough without putting a label on her. She probably wouldn't like the idea of it."* (Parent of young carer aged 12)

"I was quite upset because with the name 'young carer', it isn't something that you should be proud of as a mother… And it makes you feel like you're not a good parent…" (Parent of young carer aged 11)

3.3. Summary of the chapter

Caring is a sensitive and emotive topic for both parents and their children. From the perspective of a young carer it can be a very rewarding role which brings with it a range of positive emotional and psychological benefits including pride, improved self-esteem and family relationships. Caring had improved children's practical life skills from interpersonal skills to managing money, leading some young carers to feel more mature, independent and self-sufficient than their peers. However, caring also had adverse effects on some children and young people, including anxiety over the nature and effects of their loved one's condition, as well as other issues including stress, tiredness, strain within family relationships, restrictions in social activities and relationships, and under-engagement in education. In some cases, these led to frustration and anger expressed both inside and outside the home (e.g. at school).

Young carers developed different coping strategies in order to moderate the impact of their caring responsibilities. Older young carers recognised the value of social relationships as an outlet and protected time with friends. Many young carers shared their feelings openly with parents and some used tools such as worry books to communicate their thoughts and feelings. Within the context of education, many young carers in secondary school tried to complete homework before returning home, thereby trying to moderate the impact of caring responsibilities.

The majority of parents were keen to reduce the impact of caring responsibilities undertaken by their children and to ensure they led as "normal" a life as possible – this largely involved ensuring children engaged in social activities and maintained social relationships, and attempting to minimise the impact of caring on school engagement. There was a clear desire among parents for their children to receive support in making effective education transitions and in planning for the future. However, families did not appear to be actively preparing for their child to cease their caring responsibilities or felt that they were not able to do this.

The term 'young carer' was a familiar one to those who accessed local support services, as this was how they had been identified by services and was felt by children to reflect their caring responsibilities. It was a term that produced mixed reactions, as young carers were proud of their caring role but recognised that it was a label which carried with it

negative connotations and led to them being singled out as different. Young carers not receiving formal support services did not self-identify with the term 'young carer' and parents of these children and young people were often concerned at their child being labelled as a young carer – a label which they felt reflected negatively on them as a parent. The implication was that these parents did not want their children to access formal young carers' projects.

4. Young carer 'identification' and uptake of services: views of young carers and their families

This chapter will explore young carers' and their families' experiences of young carers' services, support agencies, health and social care service and other sources of support. It will explore barriers and facilitators to disclosing a young person's caring role in order to access support and services, including initial contact with specialist services and young carers' perceptions and experiences of undergoing needs assessments.

4.1. Experiences of contact and identification with young carers' services and support agencies

The sample of families engaged in this research included five families in which young carers were not receiving formal support services, i.e. they were not known to local support services and statutory agencies as having a caring role within the household. For the remaining families, young carers had varying degrees of contact with social services, schools, health services and local young carers' projects in respect of their caring role.

Needs assessments

Almost half of the cared-for parents/siblings (n 10) involved in the research had received a needs assessment. Where families had received a needs assessment – typically from social services – these tended to focus on the condition of the adult or sibling being cared for and the treatment/management of this condition rather than the impact this had on their lives and their future care needs. Needs assessments rarely explored the impact on the children and the rest of the family, the cared-for adult's parenting needs or the impact on wider family issues such as finances.

> *"It doesn't cover parenting because I didn't even realise that it would or wouldn't affect the parenting, you know?"* (Parent of young carer aged 9)

Young carers known to local support services were often uncertain whether they had received a dedicated needs assessment. Where they had received an assessment, most young carers did not recall this in any detail, including what was discussed or how they felt about the assessment at the time. For some young carers, this was because they had numerous interactions with social services and it was difficult to distinguish between what were general conversations and more structured assessments.

"I was asked by a social worker like what type of stuff I do to help mum and that just so they could actually know what support I would actually need." (Young carer aged 16)

Where a young carer's assessment was believed to have been conducted, this was recalled more clearly by older young carers as a discrete conversation with a series of specific questions being asked or a questionnaire being completed which focused mainly on their role, needs and feelings. In two cases the assessment had involved a discussion with the whole family and explored all their needs. Some young carers recognised MACA-YC18 and/or PANOC–YC20 when these were introduced during the interview. Most assessments had been conducted face-to-face, but in a few cases, they were carried out over the phone.

"It looked at your family needs but also it looked at what you need and when you need breaks and that because not everyone can cope sometimes and not everyone can cope with caring non-stop." (Attendee at Young Carers' Project)

For those young carers who remembered having had a needs assessment, some recalled feeling nervous before participating because it involved talking about personal issues to a stranger, while others were more concerned about the possible outcome of an assessment and what it might mean for them personally and their family. Young carers disclosed feeling awkward in the first meeting with a new professional from a support service, and recalled struggling to open up and share information about their caring role because they were either afraid of the consequences or felt uncomfortable discussing their situation with a professional unknown to them. This was overcome at the meeting when the individual conducting the needs assessment was perceived by the young carer as someone who had listened to them and understood their situation and needs. Some young carers spoke about feeling reassured during the meeting and a sense of relief that talking to a support worker was going to lead to practical help and support.

"Yeah kind of relieved about it really, we were getting someone to come and help us weren't we?" (Young carer aged 16)

The process and experience of going through an assessment were discussed in more detail with participants at the young carers' validation workshop. These young carers identified several factors which they felt improved assessments:

- Clearer communication between professionals and families regarding what the outcome of the assessment would be as well as how long the process would take to review and respond to their support needs

- Ensuring an assessment was carried out soon after the initial disclosure of caring so it did not feel like they were left waiting for support

- An assessment should be conducted in a private space at the young person's family home rather than in a formal service setting

- Flexibility regarding the assessment process - whether a face–to-face conversation or a self-completion form or questionnaire, depending on the young carer's preference

As discussed earlier, some families had ongoing conversations with social care services rather than a discrete and formal assessment focused on the young carer directly. This was often the case where disclosure and discussions with social services had not led to a direct referral for young carer support. Parents of children in these circumstances were unclear why a formal assessment had not been undertaken but assumed this was because the cared-for person's illness/disability was not regarded as severe enough to warrant help for their children, or that specialist support for young carers was unavailable (particularly where younger carers, such as those under 8 years old, were affected). In these cases parents reflected negatively on the lack of support available for their child.

> *"I used to think it's not fair on him to have to have gone through all that. I think it's affected him so bad because there should have been something to help children at that younger age, more stuff for him that he could have gone to or surrounding himself with more fun stuff instead of being worried all the time."* (Parent of young carer aged 10)

Routes into young carers' services

Among those young carers who were known to local young carers' services, initial contact had been made via the following pathways:

- Adult/children's social care services – for some, the first point of contact had been adult services regarding support for the cared-for person's illness/disability; for others initial contact had been via children's services regarding other issues, such as safeguarding and child protection; some parents had proactively contacted social care services themselves to ask for support for their child/children

- Direct contact via school – some parents and/or children had chosen to disclose the illness/disability and children's caring responsibilities to school staff in order for them to be better supported within the school environment; in a small number of cases, changes in a child's behaviour and/or achievement had been noted by school staff who had then initiated a conversation with parents and the child.

Signposting or a referral to a young carers' project had then followed from this contact

- Referral from health services – a smaller number of young carers were referred to a young carers' project from a healthcare professional. These included professionals who provided support to the cared-for individual or those who worked with the young carer themselves (e.g. psychologist, psychotherapist, counsellor) to address health and wellbeing issues that may have been directly or indirectly linked to the caring role or the impact of living with a parent/sibling with an illness/disability.

Young carers and families who were in contact with and receiving support from social care services were not always clear or able to remember whether initial contact with a social worker was related to the condition of the cared-for parent/sibling, the child's caring role or other family issues. Some families were in contact with multiple support services including social care (universal, early intervention and targeted services) and health support services, before an assessment or referral specifically relating to the young person's caring role was made.

Barriers to accessing young carers' services

Those children who were not known to local young carers' services attended school and their parent(s) had ongoing or recent contact with health and/or social services. These young carers were all from two-parent families and the majority were also younger carers (4 out of 5) so were more likely to be reliant on their parents to communicate their caring role to support services. Through our discussions with families it remained unclear as to why children did not access formal support other than the reason that their role as a young carer had never been directly disclosed to services by parents, or parents had not identified or raised a need for their child to receive support.

Through discussion with all parents and young carers, a number of barriers were identified to disclosing or seeking specific young carer support. These included:

- Concerns of parent(s) about sharing private information with professionals – in some cases it was evident that this was driven by parental anxiety about the consequences of sharing this information, with the young carer agreeing not to discuss their role with those outside the family. In a number of cases parents' anxiety was driven by fear that asking for help might lead to family separation. For several families there was a clear mistrust of social services due to negative perceptions or as a result of previous interactions. This finding supports existing evidence that young carers and their families are fearful of formal professional

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interventions in their lives that might lead to family separations on the basis of children's caring roles being disclosed (Becker et al., 1998; Aldridge and Becker, 2003); Aldridge, 2008)

"I have absolutely no faith in social services at all right now. I've dealt with them, I've worked with them for 16 years and I know the good work that they could do for people like me that would need extra help, but I worry they will just take my kids away." (Parent of young carer aged 9)

- Limited understanding about what services were available and how these would be of value to the young carer. Some young carers not receiving formal support services and their parents felt that their support needs were already addressed within the family alone, whilst others had a wider support network that helped provide support to the young carer, including friends, family members and school staff. As young carers not receiving formal support services had comparatively limited practical caring responsibilities, and parents perceived the tasks undertaken as "normal" for children of that age, there was a lack of awareness as to what benefit a young carers' project would provide their child/children

- Concern among parent(s) that the support offered to their child would be inappropriate or unsuitable. This was particularly the case where support could potentially involve the child receiving information about the parent's/sibling's illness or disability. There was concern that this information might contradict what they had chosen to tell their child, which in turn might lead to confusion, increased anxiety and stress

Young carers and their families who were receiving support from local young carers' services held similar concerns. In addition, some young carers felt that disclosing information about their caring role might mean they would be seen as letting their family down and give the impression that they could not cope or did not want to offer caring support. In a similar vein, parents reported having concerns that their child might be labelled as a 'young carer' if they were to disclose caring responsibilities, most specifically within a school setting as previously discussed in Chapter 3.

"I feel like I would be letting someone down and that I'd feel guilty for doing it… I find it hard to talk to anyone else because I feel like I'm spilling everyone else's private business." (Young carer aged 12)

However, young carers who had accessed support services, such as young carers groups and social care support, felt that these concerns were addressed through services being transparent in their communication with families, providing clear

information about how the service helped and offering reassurance that accessing a service would not reflect badly on families or be used to justify separation.

Factors facilitating access to young carers' services

The facilitators to families accessing young carers' projects were: early and effective communication of the nature of support services available to parents and young carers, and allaying concerns that seeking support for a young carer would not lead to negative judgements or consequences (such as separation of the family by social care services). Young carers and parents who had accessed young carers' services suggested that agencies needed to clearly demonstrate they had a good understanding of the issues and challenges families face in order to encourage families to discuss caring situations and access suitable support.

> *"I think they're [other young carers] just scared to see what people's reactions are … and I think to get the help and support you want, you have to speak out and ask for it otherwise you're not going to get the support.*" (Attendee at Young Carers' Project)

Some of the young carers who took part in the study suggested that where children and young people entered a new school as a young carer this was something that parents could disclose on initial registration forms. This would ensure that the school was aware of their situation but would negate the need for parents or the child themselves to go through the uncomfortable situation of disclosing their caring responsibilities to school staff directly and unprompted.

4.2. Experiences of receiving support

All young carers in our sample were receiving some form of informal dedicated young carers' support both within and outside the immediate family. However the range of support available, how this helped them in their caring role, and the extent to which this support enabled them to discuss their caring role specifically, differed amongst the young carers interviewed.

Informal support

Informal support for young carers was typically provided by parents, siblings, other relatives and friends with whom young carers spent time socialising and talking about their feelings. Access to these types of informal support was dependent on the availability of members of the extended family to provide help as well as the nature of relationships between families, their relatives and close friends. Young carers in lone parent families or

without siblings had limited informal support within the family, and those with few (or unsupportive) relatives or friends experienced little informal support outside of the immediate family. Some young people found that support within the family was not consistent due to changing family circumstances and pressures affecting parents and young carers themselves. However, where informal family support was strong, talking to other family members allowed feelings to be shared and often led to the development of better coping strategies, such as planning time out or writing about their experiences as a young carer in a diary.

> *"I do talk to my Mum about feelings because sometimes I have worries that I just want to get out… Also I have a worry book (a diary documenting the child's feelings and shared with Dad). If I keep it in my head I just worry about them all the time. But then I just get them out, it makes me feel a lot better about myself."*
> (Young carer aged 9)

Friends were often identified as an important source of support for young carers. Through peer relationships, young carers had the opportunity to engage in more "normal" activities and discussions relevant to their age. It also enabled them to discuss caring with close friends, particularly if these friends had some experience of illness/disability in their family too. Young carers acknowledged that friends did not fully appreciate the difficulties of being a young carer unless they had some experience of caring themselves. Part of the informal support network for some children included the time they spent engaged in special interest and/or sporting activities at schools or other non-caring related organisations as this also gave them time outside the home and their caring role.

The main sources of **formal support** were young carers' projects, schools and social care services (such as support from a personal key worker).

Young carers' projects

The support that young carers' projects provided varied from area to area in terms of social activities and individual support and also how frequently the projects met (weekly, fortnightly or monthly). Some parents were initially quite apprehensive about their children attending a young carers' project feeling it reflected badly on them as a parent, as discussed above, or they worried whether their child would enjoy the project and fit in with other children.

> *"I wasn't sure what it was. I was quite upset because with the name 'young carer', it isn't something that you should be proud of as a mother. So, I was a bit confused about it, not having the awareness of what is it and how it works and it makes you feel like you're not a good parent."* (Parent of young carer aged 11)

Young carers themselves, both older and younger, were often nervous about attending a project because it would involve meeting new people, but they were also curious to meet others who shared common experiences and needs. From the perspective of young carers who attended young carers' projects, these offered an opportunity to socialise and take a break from their caring role. This was particularly valuable for those young carers who found it difficult to gain respite from caring duties outside of the school environment. Young carers also reflected on the importance of having time to meet other young carers going through the same experiences. This provided an environment that helped them to share feelings which they were less comfortable sharing with friends and family members, as well as wider opportunities "just to be themselves". Parents, including those who were initially apprehensive, came to appreciate that the young carers' project was somewhere their children were freed from their responsibilities of caring, could be with peers in similar situations and "be a child again" .

> *"… a place for them to go and just not worry about things … you can just go and be kids. I think there are people there that they can talk to should they feel like they need to…"* (Parent of young carers aged 11, 12 and 16)

> *"I can't socialise but at Young Carers I can!"* (Young carer aged 12)

> *"To meet others that are going through exactly the same thing as you are so you don't feel like you're a freak and… like, no one knows what you're going through."* (Attendee at Young Carers' Project)

Young carers felt that these projects provided fun social activities (e.g. games and bowling) or opportunities to go out and socialise (e.g. cinema, art gallery and restaurants). Younger carers particularly enjoyed the games and activities which just enabled them to have fun. The projects provided a social life which, for some, was severely limited or missing, as well as opportunities to do things that they were unable to do with their parent(s) due to restricted mobility or finances. Some young carers were also given the opportunity to go on day trips and extended respite trips away from home, enabling them to take a longer break (which their family could not provide due to health needs, mobility and finances).

> *"They don't get the time to do the things they want to do. But the one thing they do look forward to is the Young Carers."* (Parent of young carers aged 10 and 12)

> *"…we get to do things our parents may not be able to do with us, like going bike riding…it gives me some time to just go out with other people who are in the same situation as me."* (Young carer aged 13)

Some young carers' projects organised specific discussions and activities related to being a young carer, including family relationships, and the practicalities and challenges of providing care. This was particularly valued by young carers of secondary school age because they felt family and friends outside the young carers' projects rarely appreciated the challenges involved in balancing different responsibilities. Where projects did not offer facilitated discussions, older young carers in particular highlighted this as something that was missing. Having this dedicated time to share feelings helped to build confidence and self-esteem.

> *"It helps you build up your confidence as well because personally I'm not a very confident person but when I come to the group it's like I'm always talking… it actually makes you feel like you are a whole person rather than someone that's always like drained from caring… you can just let it off your shoulders for a bit."* (Attendee at Young Carers' Project)

Some projects provided young carers with one-to-one support workers with whom they had regular meetings at the project, at home and/or at school. These meetings enabled them to talk privately about any concerns and to discuss coping strategies. Young carers recalled how support workers had been instrumental in helping them address ongoing problems with school, health or social care services. This had included taking an advocacy role on behalf of a child or parent. From discussion with young carers, this type of intensive support was often time limited and was missed when it ended.

> *"She helps me with my worries, things like home or school burning down. She tells me to tell her and Mum, so Mum will give me cuddle, sometimes she talks to Mum. I share my worries with her…"* (Young carer aged 9)

> *"She (Young Carer support worker) just made me feel good and she helped me with confidence as well. She was like my best friend."* (Young carer aged 11)

Some young carers experienced difficulties engaging with others in a young carers' project. For some young people it took many months to feel comfortable opening up within a group of young carers. Engagement and enjoyment of projects were largely dependent on good relationships being made with the staff and other young carers. Where challenges were experienced in forming peer relationships, younger carers tended to become attached to certain staff, while older young carers were more likely to stop attending.

> *"There were about ten girls and just me, and one lad that I didn't really have anything in common with and he was a lot younger than me. So I didn't really have anyone to talk to."* (Young carer aged 16)

Older young carers (in particular those aged over 15) were less likely to engage, or continue to engage, with young carers' projects and instead chose to spend their time with their own friends and/or people who shared similar hobbies and interests, rather than just having caring in common. For these young people the project did not provide relevant or adequate support, or was not helping them in the way they had hoped. Some had wanted support that focused more specifically on giving them information about illnesses/disabilities, caring and coping strategies, helping them to become better carers as well as planning for their future (such as employment, training and higher education). Others opted for alternative activities, such as sport, including boxing and football, which allowed them to take a break, release stress and meet friends. One young person had started attending a college support group for young carers, which gave him the chance to discuss the impact of caring with others closer to his own age.

> *"I just thought I was wasting my time. I wanted more information and advice about what is going to occur and if what I'm doing right now is good enough or anything – anything to help me."* (Young carer aged 17)

Parents' knowledge of the activities that their children participated in at young carers' projects was dependent on what was shared with them by their child. Through discussions with their children, many parents believed that projects offered the most benefit where social activities were supplemented with opportunities to talk about feelings and how to cope with emotions and stress. Parents also expressed concerns about young people travelling on their own to projects at night, particularly when transport was not provided by the organisation running the project. Both parents and young carers alike indicated that they would like young carers' projects to offer more opportunities for family social activities and support sessions, so the whole family could be more involved in the young carer's support and spend more quality time together.

Some parents had received direct support from the young carer's assigned support worker, although this was offered primarily to those families where parents were in severe circumstances (e.g. those who had been in danger of committing suicide). Parental support had included: informal discussions about how to provide better support to the young carer; assistance with referrals to their GP, and counselling services; signposting to support groups and befriending services; referrals to cared-for and young carer outings; and liaison with schools regarding children's health, wellbeing and behavioural issues.

Schools and colleges

Where families or young carers had disclosed caring to school staff, different forms of support were often provided to young carers ranging from informal staff support to more

structured interventions. Some parents or young carers (primarily older young carers) had chosen not to disclose their caring role to their school, and therefore their needs as a young carer had remained unsupported in the school environment unless concerns had been raised by staff within the school. Where caring had been disclosed to the school this occurred either:

- via the previous school or other services involved with the family

- proactively by the young carer or a parent, usually the parent of younger carers

- reactively following a discussion with the parent or young person about concerns regarding school attendance or academic performance

Some families who had not gone through a formal needs assessment had disclosed to school staff their child's caring responsibility with the expectation that this would result in additional support or an understanding of their circumstances. School responses to these disclosures did not always lead to the desired support hoped for by young carers and their parents. Anecdotal evidence gained from young carers' project workers suggested that awareness and understanding about young carers and their support needs is inconsistent across schools.

The types of support offered by schools to support young carers included:

- One-to-one dedicated teacher, pastoral or support staff offering structured or ad-hoc emotional support sessions where the young person had the opportunity to discuss their feelings and coping strategies

  "… she takes me out of the classroom sometimes and asks me how I feel and I said I am caring for my mum and she says how are you coping… and I say I just need to do it a bit more because she's not feeling too good at all now" (Young carer aged 9)

- Access to homework clubs during or after school to provide support with homework

- Help to attend after-school or out of school special interest clubs, sporting or social activities, such as providing transport or waiving charges for activities

- Leniency and greater flexibility around school and class attendance, such as the flexibility to start later or go home early to provide care, and the school providing a pass or appointment slip which enabled the young carer to absent themselves from class if they were feeling upset

Children and young people had very mixed experiences of the support they received in school as a young carer. For some young carers just knowing teachers were aware of

their situation helped them to engage in lessons. Having specific one-to-one support available for discussing feelings, home situations or to support their school studies was beneficial when it was felt to be needed. For others, support and flexibility was not provided consistently by all teachers, and in some cases this was because only a specific teacher had awareness of their family circumstances and caring role. Some young carers also felt that the timing of individual support was inconvenient and meant they missed important lessons or break times with their friends. This inhibited the degree to which they confided in teachers and therefore accessed support.

> *"I don't want to say something and then I have to stay in break… I don't want that to happen."* (Young carer aged 9)

Parents of younger carers reported that primary schools were aware of the caring situation within the home and school staff were generally perceived to be understanding and adaptive in providing flexibility and/or support to help young carers. Parents of younger carers felt that it was important for school staff to be aware of the family situation in order for their child to be better supported. Younger carers had often developed close relationships with particular members of staff who they would talk to as and when needed.

> *"Absolutely 110%… I went to the school no problems and it was like I need your help…"* (Parent of young carer aged 9)

> *"The school should understand that they're just not normal children."* (Parent of young carer aged 11)

> *"… she is a wonderful, wonderful teacher… I went to the school no problems and it was like 'I need your help' and she was absolutely amazing, absolutely amazing, she gave her a cupboard she could rip up pieces of paper in if she was angry, she gave her books to write and she's come through it swimmingly."* (Parent of young carer aged 9)

Parents were often quite engaged with their child's primary school, so were more aware of and involved with the support received than was the case for those in secondary school. However, one parent had experienced significant criticism from the school staff over how she was managing her illness and the impact on her son's behaviour. She was attending meetings at the school with the support of a young carers' support worker to try and resolve the situation (see Case Study 3 below).

Case study 3

Oliver is 9 years old and lives with his parents. The family has little contact with their wider family network due to longstanding family issues. Oliver's mother suffers with multiple physical and mental health issues, including lymphocytic gastritis, osteoporosis, fibromyalgia, lupus and severe depression. She requires daily practical support and is heavily medicated. Oliver's father works full time and has limited time to spend with Oliver because he is the primary carer for his wife. They have some physical aids installed to support Oliver's mother, but she is resistant to having home support. Oliver is expected to do small practical tasks to care for his mother (e.g. helping prepare food and tidying the house). He says he feels invisible at home and often feels anxious and frequently acts up at home and school.

> *"… now I hardly talk to her [Mum]… I've hardly spent time with Dad, Less than Mum... Hardly ever at the time I feel that I'm doing something good because I don't feel like Mum and Dad understand… sometimes stuff will happen at school or sometimes just here."* (Oliver)

> *"My relationship with him has suffered quite a bit… sometimes he's alright but on other times he just gets really angry… I really can't cope with it… his behaviour has just gone off the scale."* (Parent)

Oliver's mother finds it hard to get Oliver to and from school, but is unable to get transport provided though social services which has meant that he has missed days from school. She feels that school staff do not understand the impact of her health issues and Oliver's caring responsibilities. She has also experienced criticism by school staff of her parenting and Oliver's challenging behaviours.

> *"… it just seems as though you can cry for help all you like but that falls on deaf ears… and when I took an overdose, she (member of school staff) phoned me up and called me selfish… they make me feel like I'm a really crap parent because I do struggle to get out of bed and I do struggle to do things with him. "* (Parent)

Family support meetings at Oliver's school led to a referral to a young carers' project and a young carers' needs assessment. The young carers' project provides support including group activity sessions, 18 weeks of support from a key worker and family outings. The key worker has helped Oliver's mother liaise with the school about Oliver's behaviour and the impact of caring, and attends school meetings and family support sessions.

Oliver likes his key worker and feels he now has someone he can talk to and who understands him and the difficulties he is facing. The project has allowed him to meet other young carers with whom he likes spending time. Attending the project has also helped him develop coping strategies at home and school when he feels upset and/or angry.

Young carers who were attending secondary school felt that while there was much talk of support being offered, in practice this was not always evident in the way staff responded to their needs and behaviour. For many young people, teachers did not look to understand why there were problems completing work in school or at home or to support them to overcome these issues. Some young people, particularly those where behavioural issues had been identified by the school, had specifically not wanted certain teachers to know about their caring role. These children lacked trust in teachers and felt their caring role was used against them in a negative way, for example, caring being perceived by these teachers as an excuse for not completing their homework.

> *"They only care about the good students and getting their grades and the bad students they can't wait to get them out. I kick off quite a lot at school because I really can't be arsed being in the school when I'd rather be at home looking after my mum."* (Attendee of Young Carers' Project)

> *"Every time I was acting up, well when they say acting up when I didn't want to go to a detention or anything he'd be like oh this is not what your mum would want and all this and all that. I was like you don't know my mum."* (Young carer aged 16)

Social services

Some young people had direct contact and support from social services, however this was not always focused on the support needs of parents/siblings or young carers. As discussed previously, some families had ongoing contact with social services regarding other family issues, such as child protection and safeguarding procedures.

In general, young people had limited contact with social care services regarding their caring role. Where they did receive support this tended to be one-to-one key worker support from children's social services which involved discussions about how they were feeling and coping with their caring responsibilities and providing signposting to young carers' projects, after-school clubs and sessions with the local authority parenting team. Young carers did not always feel comfortable or happy about individual support offered by social care services and expressed concerns that social workers did not fully understand their needs or listen to them properly. In one case, there was a distrust of social services due to previous experience of information passed in confidence being relayed to the young carer's parents.

> *"He [the family social worker] doesn't listen to me that much, he writes down something different [to what I say]."* (Young carer aged 9)

In some cases, young carers only had contact with adult social services indirectly when visits were made to support the health and wellbeing of the cared-for person. Some young people had experienced difficulties trying to access medical, practical and emotional support for their cared-for family member and, consequently, felt very frustrated and angry about perceived inaction from social services. As previously discussed, there was also an underlying concern that disclosing the urgency of parental needs may lead to unintended consequences such as a child being taken into care.

> *"I just want you to help my mum because otherwise she's going to kill herself and they were like we can't actually help until she's done something. It was like, well she'll be dead then and then you can't do anything."* (Young carer aged 17)

> *"The most important thing is they shouldn't wait for you to say I want to kill myself before they give you the help and support… Because you have to be really bad to get the help but if you say you're really bad, it comes with the consequences."* (Parent of young carer aged 11)

Other forms of formal support

Other formal support services accessed by young carers tended to be focused on supporting their mental health and wellbeing. Some young carers had accessed Child and Adolescent Mental Health Services, counselling support, Cognitive Behavioural Therapy (CBT) or family therapy, although these had been in relation to other family issues (e.g. domestic violence and family separation) or personal issues (e.g. bullying, self- harming and behaviour management) rather than as a result of their caring role directly. One young carer had attended an awareness session on anxiety and mental health with social services while at their young carers' project which was viewed as beneficial.

Cared-for family members also received health and social care support. As previously described, this included occupational therapy, practical adjustments, provision of wet rooms, physical aids and equipment, and carer support home care services, e.g. a carer providing support for a couple of hours every day or for a day every so often. This support often helped to make the cared-for person more independent which freed up children's time spent on caring tasks or gave the family more free time to spend together.

> *"She loves it when the carer comes because it's a break for her. She gets excited…"* (Parent of young carer aged 11)

However, some young carers felt excluded from discussions about their family member's illness/disability with medical professionals, in particular regarding medication and how it should be administered to enable them to assist the cared-for person if help was needed.

Some families had developed their own strategies to help children understand and assist with the cared-for person's medication, for example, developing colour charts to highlight which medication was taken at certain times of the day or colour coding different medications.

> "*Well say if the person you care for goes into hospital they won't necessarily talk to you… they would just generally speak to the adult rather than the person who's actually giving them the medication because, yes, fair enough, they're* [the young carer] *underage to actually administrate the medication, but actually they're the only person in the house at the time to administrate the medication.*" (Attendee of Young Carers' Project)

Some older young carers had accessed online support groups and social media for young carers (by young carer support and advocacy organisations) to make contact with other young carers and discuss issues such as how to cope with caring. These sources of information, advice and support had the advantage of being accessed flexibly whenever and wherever suited the young person – as long as they had access to a computer.

4.3. Summary of the chapter

Under half of the families in the research sample had received a needs assessment for the cared-for parent or sibling. It was rare that these involved an assessment of the impact of the condition on the family and/or included needs assessments of children or whole family assessments. Most young carers were unclear as to whether they had received an assessment and, where they had, they often did not recall this in any detail. Needs assessments could be improved by ensuring they are conducted promptly following disclosure, in a private setting, in a location chosen by the child, and with clarity in respect of the outcomes of the assessment.

Young carers typically accessed young carers' services via referrals from adult/children's social care, school, or adult/children's health services. The five young carers not receiving formal support services in the sample – those not accessing young carers' support – were all from two-parent families and tended to be younger children with relatively fewer caring responsibilities.

Parents highlighted barriers to accessing support that included concerns about the consequences of disclosure for families (and what this would mean for their children), lack of understanding of the nature of support available, and concern as to the appropriateness or efficacy of support. Conversely, early and effective communication of

the nature of support services, and allaying parental concerns around the consequences of requesting/accessing support, helped to facilitate access to young carers' services.

Informal family support – talking and/or sharing responsibilities with family members – was a key source of support for many young carers where available, helping to reduce stress and develop coping strategies. Likewise, friends and time spent engaging in social activities helped young carers to feel more "normal" and engage in non-caring related conversations and activities.

Young carers' projects were an important source of formal support for young carers. While young carers and parents were initially apprehensive of attending a project, this was quickly overcome and most young carers found projects a place to gain respite from caring. Having caring in common made it easier for these children and young people to open up in conversation about caring – something that was valued. Projects also provided access to fun activities, as well as information, advice and advocacy, although provision varied across groups. As young carers became older it was evident that they sought to engage with a wider peer group, and relied less on young carers' projects. Young carers and parents both expressed a desire for young carers' projects to provide support for families to spend more time together.

Some schools provided support to those children who were identified as young carers, ranging from personalised teaching/pastoral support, access to homework clubs or afterschool provision, and greater flexibility in school/class attendance. The actual experience of support varied greatly among young carers. In some cases support reduced the emotional and educational impact of caring, but in other cases it was inconsistently provided due to a lack of shared information/understanding between teachers.

Children's social services had limited contact with young carers about their caring role, although some did have a key worker who discussed the impact of caring and made referrals to young carers' services. Often contact with social services was in respect of the cared-for parent/sibling, or as a result of other issues within the family. There tended to be a high degree of distrust in social services because families were worried about the appropriateness of support and family separation, and therefore both children and their parents were reluctant to disclose information about caring responsibilities for fear of potential repercussions.

Other support accessed by some young carers was delivered through health services (e.g. CAMHS), although this tended to be for wider issues experienced by these children (e.g. coping with family breakdown or bullying) rather than their caring role specifically. Some young carers discussed the health support that their parent/sibling received. While

this was seen to be beneficial by some young carers, others said they would like to be more included in discussions that took place between parents and health professionals.

5. Support propositions: views of young carers and their families

This chapter will explore young carers' support needs in relation to perceived gaps in current services and responses to a series of support propositions which were developed using previous research with young carers and initial scoping interviews with local and national stakeholders.

5.1. Overall gaps and improvements identified

Through discussion with young carers and their parent(s) about current support needs and experiences of young carers' projects, a number of factors were identified which would help either to promote more accessible provision or to meet gaps in current provision. These included:

- to ensure that young carers' projects were convenient to access (i.e. near transport links and centrally located); ideally these would also provide transport to and from services where required

- to make provision available to younger carers (i.e. those under 11 years of age), so younger children would not have to wait so long before being able to access support services

- to make young carer services available soon after the initial need had been identified to ensure that services are making appropriate referrals

- to ensure that referral agencies (social services, health services etc.) are in a position to provide more information about and to raise public awareness of young carer services so they can provide reassurance to children and young people and reduce the likelihood of young carers remaining 'hidden' to specialist services

- to ensure that school staff, health and social care professionals have a greater understanding of the impacts of caring, support strategies appropriate to their role/setting, local service provision, referral pathways, and signposting

- to deliver age appropriate support and activities through young carers' projects to ensure that the different social, emotional and practical support needs of young carers at different ages are acknowledged and catered for

- to provide access to age appropriate sources of information, particularly for younger carers, about their family member's illness/disability. This would include

covering aspects such as diagnoses, prognoses, impacts, and treatment, and could be delivered by a health care professional or a carer with similar experiences. Ideally it would be someone the young carer knew so they could tailor information to their individual needs

- to provide joint family support to address the need for more social time and holidays as a whole family

- to improve support for cared-for family members to include emotional, psychological and/or practical help (e.g. counselling, physical aids, home help) to reduce children's and other family members' caring responsibilities and enable more free/family time

5.2. Views on the usefulness and impact of potential support propositions

Young carers and their parents were asked for feedback and comments on the support propositions which were developed following a review of relevant literature and interventions discussed by stakeholders in an earlier phase of scoping interviews. A complete list of all the propositions shown is provided in Appendix A.

All young carers and their parents were shown cards which explained each proposition and were being given the opportunity to make alternative suggestions for support to help them or others in their situation. Parents and young carers identified the types of support that they felt would benefit them or their children. Through discussion with families it was apparent that propositions were grouped into six types of support: emotional and social support; practical support and information; educational support; financial management; support with life planning; and respite care.

Almost all young carers and their families agreed that emotional and social support and practical support and information would be of value. In some cases children and families had wanted these forms of support but were not aware that they existed. Depending on the situation of the young carer and the type of support being offered, some families were more resistant to other new or different support propositions (such as educational support, financial support, life planning and respite care) and had mixed views about their potential utility in addressing the needs of young carers and their families.

Emotional and social support

Young carers did not spontaneously discuss the need for emotional support, but through discussion of propositions relating to the availability of 'someone to talk to', it was evident that emotional support was an important need. Two propositions that were commonly identified by young carers of all ages were: support providing **someone to talk to about stress and worry;** and **someone to discuss relationships with**.

The third proposition – **having someone to share information and experiences of caring** –young carers felt this was a similar need to having someone to discuss concerns and relationships with. Young carers often suggested that this should be another young carer so that they could learn from each other's experiences. Young people who accessed this type of support from young carers' projects, or informally though friends, stressed the value of sharing experiences with peers and knowing there were others in a similar position to themselves. Those who had not received this type of support anticipated it might be helpful to speak to other young carers. Ideally these would be young carers who were of a similar age, caring for parents with similar conditions or experiencing similar challenges (e.g. family breakdown). As well as providing an opportunity to share experiences and provide emotional support, these relationships were also seen by some as a way of gaining information that would help them be a *"good"* or *"better carer"*.

> *"If I was to talk to other people, like children, I wouldn't want to talk to children whose situation was different. I'd want to talk to 10 year old boys who had had two depressed parents over the past couple of years. I would want to see how they dealt with it. I want to see what their parents were like, I want to see new methods in making my parents feel better."* (Young carer aged 10)

> *"I think this might be useful because if they're struggling and then both of you are going through the same problem you could help each other out."* (Young carer aged 13)

Those who had received support from older young carers within young carers' projects reflected on the benefits of talking to others slightly older than themselves as they were able to relate to their own past experiences as a younger carer.

> *"You could have someone your age in a similar situation where they know what it's like and everything and you can talk to them about it and then it could also be someone who's older who's had to deal with it since they were your age and they could be like a positive role model for you because that shows that you can actually deal with it."* (Attendee of Young Carers' Project)

Most young carers were also open to talking to a familiar adult professional, such as a teacher and/or young carers' staff, regarding their feelings and other factors impacting on their wellbeing (e.g. bullying, difficulties making friends at school, anger and behavioural problems). Some older young carers, who had disclosed caring to school staff, expressed concerns about disclosing within a school setting as has been previously discussed. Young carers not receiving formal support services were unlikely to see adult professionals as the conduit through which to discuss their emotions or relationships; instead these conversations would be with friends or family. For adult professional support to work effectively as a source of emotional support it was important for the adult to be open, non-judgemental, and provide consistent and reliable support as trust needed to be built up over time to support open and honest discussion.

> *"… a proper professional would just make me like proper nervous… like a heavy load has been lifted onto me and it's just like you've got to handle it like an adult."* (Young carer aged 12)

Some young carers suggested that opportunities to talk to other young carers of a similar age could be provided through buddy systems and social media. Phone help-lines or text services were also suggested as useful if young carers needed to speak to a professional for help.

> *"I like texting. So, say if I had a problem, I could text someone about it and then see how to manage that."* (Young carer aged 12)

While some liked these ideas, including young carers not receiving formal support services, as they would enable them to access information or support without meeting professionals face-to face, others expressed concerns about confidentiality and not knowing what might happen with the information they shared. Younger carers were most cautious about not knowing who they would be talking to and how safe these options would be. Many parents, particularly of younger carers, were also worried about the privacy of online, phone or text support services and preferred the idea of face-to-face support.

The majority of parents thought that it was beneficial for their children to have someone outside the family to talk to regarding their caring responsibilities, experiences and concerns. Some also felt that more formal emotional support – i.e. through counselling or psychotherapy - would be helpful for those young carers who were struggling to cope with caring responsibilities and/or other challenges (including bereavement and family breakdown) which may compound the challenges of caring. However, some parents of hidden young carers and others with limited peer/family support networks, were concerned about how comfortable and confident their child might be talking to someone

outside their current support network. There were also concerns that these sources of support may have the potential to cause children greater anxiety if not managed appropriately. This was less of a concern for children accessing young carers' projects and most parents were highly receptive to the idea of peer support through dedicated young carers' projects.

> *"Some kind of youth club for carers… where they can just go and meet people… to know that she's not the only person out there… where there's like services, where they can play sports or something and vent frustration and perhaps have a counsellor on site if they have anything they want to talk about…"* (Parent of young carer aged 9)

As discussed earlier, many young carers, particularly older ones and those in lone parent families, felt that caring impacted on their social life, reducing the time they spent with friends, or on hobbies and sports.

Another proposition tested with young carers and families was around **supporting the young carer's social life**. Those children and young people who had attended young carers' projects were generally very positive about the opportunities they provided for meeting other people and taking part in activities and trips. These projects offered children/young people time and space to relax, meet and make friends with other carers of similar ages. During the interview, young carers' feelings of guilt and worry about leaving their parents/siblings was never mentioned in the context of attending young carers' projects; it is possible that children's anxieties were reduced through the opportunities projects provided for children to talk openly about their caring experiences in a supportive environment. Children and young people's views on young carers' projects are detailed in Chapter 4.

Parents were keen on the kinds of support which allowed their children to have a more active social life, particularly when their own condition (or family circumstances) limited family social activities. Parents did not necessarily see this as being dedicated young carer support, but instead for their child to be supported in pursuing their own interests and to be provided with opportunities to flourish as children and young adults. However, young carers' projects in which children and young people had the opportunity to socialise and talk with other young carers in a safe environment were appealing to the majority of parents.

> *"I think this would be beneficial for her. It's really important for her to meet people who have got similar responsibilities… not just people her age I think… for her to be able to have someone to talk to about things so I think that would be priceless, absolutely priceless."* (Parent of young carer aged 12)

Some parents were less engaged by the proposition around supporting social life because they felt that their children already had sufficient social activities and interests in their life.

Practical support and information

Where relevant to the condition of the parent, and the extent of support currently available, a number of parents and young carers identified with the proposition: **making caring easier, including practical aids and equipment or extra help and/or information from a professional which could make caring easier.**

Practical aids and equipment to help make the cared-for person more mobile and safe (e.g. bath lifts, rails) were identified as ways to help reduce both the physical and emotional caring responsibilities of young carers. While parents recognised the value of these in most cases, and appreciated that these aids were likely to become more essential in the future, there were also concerns raised about the cost of these items, and in some cases a reluctance to accept that these were needed. This would appear to suggest that parents had not received an adequate needs assessment for themselves, and was particularly the case among parents of young carers not receiving formal support services.

> *"… more practical stuff to help Dad get around easier, instead of having to swivel around everywhere… Find out what else I could do to help, because at some stages I just feel hopeless."* (Young carer aged 12)

> *"It's all about, you know, changing the bathroom and putting double rails up. I said, ooh, hang on. It was like as if you were going to be labelled as disabled and I didn't want that… We've worked out our own system.*" (Parent of young carer aged 12)

Many parents wanted more practical help and emotional support for themselves or the cared-for sibling to enable a better quality of life for the family a whole as well as minimise the caring responsibilities of their children. This included caring support for the cared-for person, domestic help, and getting children to and from school or social/sporting activities. Some parents did raise concerns about receiving formal social care and health support both in respect of the quality of the care being provided and that this involved an outsider undertaking sensitive/personal caring duties. Parents and young carers who had some experience of receiving social care support and health support had mixed experiences, including variable standards of the quality of support and a lack of staff continuity, making it difficult to build up established and trusting relationships.

"I wouldn't trust anyone I don't know to come in… I want to get to know them first before I trust them." (Young carer aged 11)

"The children have not been able to deal with some of them (carers). It's been absolutely terrifying for them finding complete strangers in the house … It chops and changes, one day you've got one person, next day you've got another person.." (Parent of young carers aged 11, 12 and 16)

Parents with more unpredictable illnesses/disabilities (including ME, epilepsy, depression or personality disorder) believed it would be challenging to draw practical benefit from formal caring support from outside of the family due to the unpredictability of their condition(s). Parents highlighted that support was not necessarily available during the onset of a particular episode of illness which is when children struggled the most. Through discussion it was evident that emergency or crisis support (i.e. the need for rapid intervention) continued to be a serious unmet support need for young carers.

"If I was to fall and be in a position where she can't move me, it then stresses her out more, so that's how she feels alone. So I think that's the only problem, really. I don't think there's any kind of equipment or anything that's going to stop her from feeling alone when she's alone." (Parent of young carer aged 9)

Young carers indicated that support for the cared-for person to become more socially active may be valuable. Increasing the independence of the cared-for person could reduce the physical and emotional demands placed on young carers as well as help free up more time for them to spend on their own social activities and interests.

In general, young carers thought that having access to **more information about their family member's condition** would be beneficial. Many young carers, of all ages, felt they did not have full understanding of their parent's/sibling's illness and that being more knowledgeable might help reduce fear of the unknown, avoid misunderstandings about the form of care they required, and as a result increase their confidence in supporting their parent/sibling. Young carers of parents with mental health conditions had particular difficulties understanding the nature of the condition and were sometimes unsure of that the information relayed from the cared-for parent was correct and accurate.

"I still don't have a really good understanding of what my mum's problems are so if I knew what it was then I could do things that would help her for the future. I think it might be best to either talk to someone in person or get it from a website."
(Young carer aged 13)

Young carers indicated that more information should be provided at the point of, or soon after, diagnosis and on an on-going basis thereafter as the prognosis and support needs

changed; this also supports findings from previous mental health research (see Aldridge and Becker (2003); Falkov's (2013) findings which suggested that mental health professionals should always ask their patients if they are also parents. Ideally information should be provided about the nature, diagnosis and prognosis of the illness/disability e.g. its causes and effects, how things may change over time and the condition is treated. It was suggested that information could be accessed from a range of sources, dependent on individual preference, including health care professionals, young carers' projects, and through information leaflets and online resources. Older young carers also suggested that adult carers or others with personal experience of living with someone with the same illness/disability might be helpful to talk to and provide them with useful (and non-technical) information.

> *"If someone sits you down or something and explains exactly what's happening and that like it's easy enough for you to understand, like then it'll be a little bit more beneficial than doctors using like really big technical words that you don't understand but like the adult carers could understand because they've dealt with the medication and that for so long."* (Attendee of Young Carers' Project)

Most parents welcomed the idea of more information and understanding about their illness/disability for their children. This could be directly from a health care professional or alternatively parents could receive help from healthcare professionals to explain things better to their children.

> *"If it was like somebody, a professional from the hospital, to explain to [name of young person], that would have been helpful… they could have explained you know a lot better than what I did."* (Parent of young carer aged 16)

One parent suggested the use of creative and playful techniques (e.g. workshop days or plays/puppets) for younger carers which could be delivered by health care professionals or young carers' support staff. As discussed previously, some parents raised concerns about the possible emotional impact of receiving more detailed information about conditions, particularly if it was delivered by professionals who did not have an established relationship with the child. It was important to all parents that information was delivered in age appropriate and sensitive ways according to the child's needs and best interests, and was tailored appropriately, ideally by someone who the child trusted.

> *"I think having the information is great but it needs to be delivered in a controlled way, so someone where they know the child and is going to put the child first to make sure they aren't delivering things that they mentally, emotionally aren't ready for… and I think [from] someone who actually understands the child and the situation rather than someone who may understand the mechanics of the illness,*

the condition whatever but doesn't know the child." (Parent of young carer aged 10)

Other propositions received a more mixed response regarding how helpful or useful they would be, these included the following:

Educational support

Young carers expressed diverse views on how helpful **support at school** could be, often reflecting previous experience at schools where caring had been disclosed. Older young carers in particular were dismissive of the support being offered by schools to identified young carers as they had experienced this negatively or in a tokenistic way in the past as discussed in Chapter 4. However, there was a clear desire among a number of young carers for school staff, particularly in secondary schools, to have a greater awareness of children's caring responsibilities and the impact of these (as directly illustrated in the quote below from a young carer who had not received formal support services).

> *"Say if I'm handing in homework and I couldn't do it because there was no-one to help me, or there was a problem at home, they don't understand that. And I'd like them to know that, because it's unfair."* (Young carer aged 15)

Spontaneous responses from young carers on the form of educational support desired centred around support for their studies rather than emotional support. This included teachers providing more help with their studies and greater flexibility on deadlines for home/coursework, and schools providing after school homework clubs and quiet spaces to do homework during breaks. A small number of young carers (particularly younger carers and young carers who were not receiving formal support services) felt they were achieving well at school and that no additional academic support was needed to support them as a young carer.

School was not seen as a place where most young carers would expect to receive emotional support. However, some younger carers had very positive experiences of emotional support at school and were happy accessing this where available. For older young carers there was not the same degree of interest in or access to emotional support within a school environment. Talking to friends, parents, young carers' projects and online sources were more acceptable avenues for this type of support. However, school was always seen as somewhere that young carers should be able to receive this form of support if needed.

> *"I think school's like a backup plan. Like, if you've done, like, all of that, and you still don't know what to do and, like, your friends aren't replying or you've fallen out with them, and you don't want to ask your parents or you don't want to, like, ask*

anyone on social media, I think school will always be there." (Young carer aged 12)

Many parents felt it was important that school staff had an awareness of children's caring responsibilities and the impact this would have on them/their studies. Some parents who had experienced less than adequate support for both themselves and their child/ren called for there to be training for staff on working with young carers. Issues affecting support provided within schools are discussed in Chapter 4.

Financial support

The financial support proposition was specifically in relation to **providing advice for young people who manage money or finances and might want advice on how to do this.** Most young carers had no involvement in managing family money or finances at home, apart from some older young carers whose cared-for lone parent or sibling struggled with this task by themselves. These young people wanted to be able help make more informed decisions about money management, budgeting and, in some cases, other financial or practical support available for their loved one (e.g. making benefits claims) which could help to improve their independence and quality of life.

> *"…no-one tells you, you just have to kind of do it, don't you? You don't go to school and then they tell you how to do budgeting, you just have to try your best."* (Young carer aged 17)

Many other young carers, despite not having any involvement in family finances, were also interested in learning more about money as they thought it would be helpful for when they became more independent. Likewise, parents felt education and advice on finances would be very useful as a general life skill rather than a specific caring related need.

> *"I would want to learn how to do it so I could help Mum when she's, like, going through the bills and stuff. So she knows, like, she doesn't have to do it on her own and then I would also be there if she needs any help."* (Young carer aged 12)

Support with life planning

Support around future life planning - **talking to someone about what they want to do when they get older, including work or going to university** - was of more interest to older young carers (aged 15 years and above) as they began to think about their plans post-secondary school. The general careers advice available within school was seen as helpful but there was a strong desire for more specific discussions around the challenges children and young people face as young carers in working toward their own, independent lives. These included overcoming some of the emotional and psychological barriers that may be faced by young people deciding to leave the family home and how to

ensure adequate support was available for the cared-for family member and siblings at home.

> *"I want to be a nurse and I know you have to study hard for that… But then you think about all the possible reasons why not to go but then why to go. But you're, stuck in the middle."* (Young carer aged 12)

Younger carers did not see the value of support with life planning currently in their lives. Due to their age this proposition was seen as less important but recognised that it would be useful at a later date when they had more decisions to make about their future.

Parents said that discussions about the future were very important and wanted their children to receive this sort of help and advice, but this was not seen as a priority in comparison to providing support around more immediate needs (e.g. relationships, school performance, school attendance etc. - as detailed in Chapter 3.1). Support with life planning was also highlighted as being of value to cared-for siblings to help them become independent adults where possible. A small number of parents were adamant that they would not allow their children's caring responsibilities to adversely affect their future plans and independence, particularly parents of young carers not receiving formal support services. For these parents the value of support with life planning – beyond that offered as standard by schools – was discounted as not of relevance to their children.

Respite care

Young carers had conflicting feelings about wanting to have more time for themselves, the potential impact this may have on the person they cared for, and feelings of anxiety, selfishness and guilt. Most young carers were keen to do as much as possible to help with practical and household caring tasks, and therefore a proposition focussing on **support to stop or do less if a young carer wants to take a break from caring** provoked complicated emotional reactions. Some young carers reacted strongly to the idea of stopping caring altogether as it seemed to suggest they no longer cared emotionally about their loved one.

> *"… it's like yes I know it gets tiring but it's like I'd never stop caring for my brothers because ... it's something I've been doing for years you couldn't just stop."*
> (Attendee of Young Carers' Project)

In principle young carers had some interest in the proposition, but only in terms of "taking a break" rather than doing less or stopping caring, even though indirectly a break would result in doing less or stopping temporarily. Breaks from caring were seen positively by young carers as opportunities for them to relax and de-stress, enabling them to return to caring responsibilities feeling refreshed. Young carers who had experience of young

carers projects, outings and respite holidays were typically very positive about such opportunities to take a break away from home and to meet others in similar situations, as discussed in Chapter 4.

Many young carers did express concerns about taking breaks if the cared-for person needed support from them while they were out of the home. They needed reassurance that there would be someone else able to provide the care they would normally deliver themselves in order to engage in respite care. As previously discussed in relation to practical and information support, this carried with it associated concerns around support being provided by care professionals unknown to the family.

> *"Do you know what, sometimes I do feel a bit, worn out by doing things for my Mum, but no, I would not take a break, I would only ever take a break if they're okay."* (Young carer aged 10)

5.3. Summary of the chapter

A number of factors were identified by parents and young carers that would promote access to support for young carers. These included: increasing the inclusivity of young carers' services (e.g. catering for younger carers and enabling access through central locations/transportation); ensuring that the availability and nature of young carers' projects are communicated quickly and effectively; providing age appropriate activities and information across all young carers' services; and improving support for cared-for family members to help meet diverse needs.

Propositions that related to **emotional and social support**, and **practical support and information** were most appealing to young carers and their parents. There was recognition that young carers could (and did) benefit from having someone to talk to about concerns, relationships and the experience of caring and to have opportunities to meet and talk with other young carers of a similar age. Practical support through aids/equipment could help reduce caring responsibilities but they also brought with them concerns around cost and stability of professional care. Information from professionals were also seen, in principle, as useful for supporting young carers that wanted further information on parent/sibling medical conditions, though parents had some anxiety about the accuracy and impact of this information on their children.

There were differing views among young carers of the value of **support at school**. Both parents and young carers wanted to reduce the impact of caring on their education, and a greater awareness among teachers of the caring situation was seen as a way of achieving this. Effective support could be achieved through all teachers having a clear

understanding of the nature of children's caring responsibilities and providing extra support around stressful periods such as exams and transition points.

Financial support (through advice around money management) was most relevant for older young carers, particularly those aged 16-17, who were more likely to be involved in managing finances within the home, however younger carers also expressed an interest in learning more about money. Likewise, support with life planning was also seen by young carers and parents to be valuable support, though most relevant for older young carers nearing independence.

Support in stopping or reducing caring responsibilities through providing respite and activity breaks from caring were support propositions that most of the young carers and their parents responded to positively. Younger carers wanted more opportunities for activities/breaks with other young carers, whereas older young people tended to want to spend more time outside of the home with a wider group of friends (i.e. not just other young carers).

In offering recommendations to policy makers and support services, young carers expressed a desire for staff in support services – notably education, health and social care – to have a greater understanding of the challenges and needs of children with parents/siblings who have a disability/illness and their caring responsibilities. Support services should look to empower young carers through information and activities that support children in established caring roles to adopt coping strategies and help children transition out of caring.

6. Conclusions

6.1. Key Findings

The results of this study confirm those of other studies in that children and young people with caring responsibilities experience a range of both positive and negative outcomes as a result of these responsibilities, and that these outcomes are directly affected by the level of informal or formal support they receive. There are a number of factors that were found in this research that had an impact on the identification, support and experience of young carers, many of which have been identified in other studies on young carers dating back over the past 20 years. This qualitative study into the lives of young carers helps provide an up-to-date understanding of the current context of caring among children and young people at a key point in time, with the introduction of the new legislative framework (the Care Act 2014 and the Children and Families Act 2014).

A common theme throughout the research is the importance of early intervention and the critical role that *all* statutory services have in assessing and supporting families holistically. The findings from this study are congruent with the principles and guidance set out in the legislative framework. These principles promote the need for whole family approaches when working with young carers and their families as well as the need for professionals to consider young carers' needs not only as carers but *also* as children (see also Association of Directors of Children's Services, Association of Directors of Adult Social Services, Children's Society and Carers Trust, 2015; and Department of Health, 2015). These findings are consistent with previous research and echo the ongoing need for raised awareness and understanding of the need for holistic, whole family approaches to needs assessments and support among all professionals.

Below we summarise some of the key findings from this research, making reference to wider research or practice developments where appropriate.

Early interventions are critical in ensuring that children do not take on inappropriate caring tasks; the need for children to provide care is increased when services to ill or disabled adults (or other family members) are inadequate, inappropriate or missing and when family based interventions are not provided

- Children and young people should not have to become carers. There is a need for good universal services and early intervention to prevent this. It is important that ill/disabled adults (or other family members) have the right kind of support in order to ensure their children do not take on inappropriate or long term caring responsibilities.

This includes ensuring appropriate support for all family members during particularly critical periods (e.g. school holidays)

- Parents were often keen to protect younger carers from the impact of caring, whereas older young carers took on more responsibilities over time, potentially as they became more accustomed and skilled in caring.

- The research highlighted the tension that existed between parents' desire for their children to have a "normal" childhood and their capacity to fulfil this objective due to the availability of support. This was particularly the case with less stable conditions – such as mental health conditions – where families were not always effectively supported by health services and during extended periods of time where children remained within the home environment (e.g. school holidays).

- It is also important to recognise that children who live in families affected by parental/sibling illness/disability will have wider needs that occur because of this; caring may be just *one of* the consequences for children of living in families affected in these ways.

- Early intervention should also involve ensuring that children and families have access to appropriate information about the parental/sibling condition and the support services that are available to them. This information could be made available from a range of sources, dependent on individual preference, including health, education and social care professionals, specialist organisations, charities, young carers' projects, and through online channels.

Social care, health and education professionals have a crucial role in identifying and assessing the needs of young carers

- Transition support provided by health (including GPs and CAMHS) or social care professionals needs to take into account the whole family, with both parenting needs and the needs of dependents being assessed. It is critical that the wider needs of children are recognised in assessments (as well as in service delivery and support) – e.g. as children in need (and as carers when young caring has become established in families). There exists a range of guidance to support a whole family approach to providing assessment and support (e.g. Department of Health, 2015).[6]

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[6] See also SCIE Transition in the Care Act 2014 and the Children and Families Act 2014

- Needs assessments of young carers need to be conducted promptly – i.e. as soon as possible following disclosure of caring responsibilities – and result in actions to provide support to prevent or ease the extent of caring undertaken.

- Between April 2015 and March 2016 the Carers Trust and The Children's Society are delivering a Department for Education funded project[7] 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. Learnings from this project will be disseminated across all local authorities in England to support the replicability of effective approaches. This current research highlights the potential value of this project in supporting collaborative, holistic, whole-family approaches to identifying and supporting young carers.

<u>Limited support for either the young carer or their cared-for parent/sibling, accompanied by a lack of understanding of the parental/sibling condition(s), can exacerbate the adverse emotional effects of caring among children and young people</u>

- Our study found that many parents did not have the confidence or medical knowledge to communicate effectively with their children about the parental (or sibling) condition(s).

- Young carers (and their parents) need to be supported more effectively to understand and to discuss their conditions with family members and wider support services. Importantly, this includes support from primary care services (GPs, for example) where young caring is likely to be identified. This would help increase children and parents understanding of these conditions and their impacts, in turn helping families to manage conditions so that the impact on children is minimised.

- Additional research to understand at what age parents feel able to discuss their illness/disability openly with a child would be valuable in informing the form of support that parents receive in communicating this information to their children. Research with a larger sample of young carers would also be beneficial for understanding at what age children/young people begin to take on caring tasks that are likely to have a profound impact on their childhood and transitions into adulthood if left to care unsupported.

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[7] Making a Step Change

Parents and children alike remain concerned about the consequences of disclosing young caring in families, meaning children and young people with caring responsibilities, and their wider needs, can go unrecognised and unsupported

- Previous research has found that children are 'socialised' into caring roles because of the lack of recognition and support at the point at which children take on caring responsibilities, and because families fear disclosure (Dearden et al., 1994). This current research found that families continue to be fearful of disclosure and what this might mean for them, despite the advances made in policy and practice in the UK. This reluctance could be influenced by a lack of awareness of support services and/or a fear that disclosure may have unforeseen implications for the family.

- Children and parents alike also do not necessarily identify with, and have anxieties concerning, the 'young carer' identity (or 'label') due to the negative connotations this could have for them and their child.

- Access to support services was dependent upon parents (and their children) having their fears of the consequences of disclosure allayed by professionals and of having a good awareness and understanding of what support services were available.

- For some families, the needs of children who live in families affected by parental (or sibling) illness or disability need to be identified and met in other ways – i.e. not relying on disclosure of caring responsibilities to professionals in formal health or social care support services.

- Further research may look to understand why families are still fearful of interventions from social services and from other interventions/services where children's caring roles may be identified.

The ongoing challenge in identifying and engaging with 'hidden' young carers

- This research aimed to include 'hidden' young carers, who were identified and recruited onto the study through online panel data. As has been the case with past research, engaging hidden young carers proved a challenge because these children and families have not (and possibly do not want to) disclose caring responsibilities within the family. Through online panel data this study was able to identify families where a child was performing caring responsibilities though challenges were experienced in recruitment due to (i) the accuracy of the reported caring activities or

contact information, and (ii) language barriers. Furthermore, on reflecting on the wider sample of young carers in receipt of support services, and the wider literature, it was apparent that the form and extent of caring in these families was less pronounced and harder to distinguish from children providing general support around the home.

- While it is sometimes claimed that there are potentially high numbers of unidentified and unsupported young carers in the UK, particularly by campaigners and charity groups, there is currently a lack of robust evidence to substantiate estimates of this 'hidden' population. The second quantitative phase of this current research should give us greater insight into the numbers of children who are providing informal care in England, including those who are known to services and those who are not.

- Given the challenge that exists in identifying hidden young carers it is crucial that all services working with vulnerable children and adults take a holistic approach to assessing need as is supported through the Care Act 2014 and the Children and Families Act 2014. Further research may look to explore what social care, health and education services are doing to identify young carers and to support them where appropriate.

The importance of support in helping young carers (and their families) to moderate the impact of their caring responsibilities and to prepare for adulthood (transition support) should be recognised

- Information on support services for parents with illnesses or disabilities, and for their children, should be openly accessible and actively provided by health and social care professionals. This should clearly communicate what support is available, who it is for, and how it can be accessed.

- Young carers and their parents highlighted the valuable role that young carers' projects play in providing young carers with a social and emotional outlet. However, provision appears to be variable in the range of support offered, and is not always tailored to different age groups. Such provision is also only available to those children and young people where caring roles have been identified.

- Young carers' projects should not be offered in place of or simply in the absence of other health, education and social care support, in helping them to understand the parental/sibling condition, in accessing social activities, and in helping them make successful transitions into adulthood, including further/higher education, training and work as is recognised in the provisions of the Care Act.

- Health, social care and education professionals should work to build the resilience of young carers and reduce anxiety at times when parents/siblings are left alone. Included in this personalised approach should be provision of financial/money management advice and age-appropriate information about specific illnesses/disabilities.

6.2. Messages from children and families

To conclude this report it is worth returning to those issues which are most pertinent for the children and families who took part in this study. During the interviews with young carers and their families a number of key messages emerged that are important to reiterate. These messages centred on the need to increase the awareness and understanding of staff in support services of the needs of families in which parents/siblings have a disability/illness. The key messages from young carers and their families are discussed below:

- **Improving support for cared-for parents and siblings to minimise the impact of caring responsibilities on young carers and other family members.** While this support may be focused on the parent/sibling illness or disability, the desired outcome was for this to reduce children's caring responsibilities and promote greater stability within the home (e.g. the opportunity to spend more social time together as a family).

- **Providing more age appropriate information regarding the cared-for family members' illness and disability** to increase children's awareness and understanding of the nature and impacts of their family member's health. This in turn would help to reduce children's anxieties and increase their sense of control within the home environment.

- **Staff working in support services, across education, health and social care, should have a clear understanding of the challenges faced by young carers** and the range of support needs that they may face. Support services should also actively put in place support strategies or make referrals to local provision in order to minimise the impact of caring on children. This could be enabled by professionals taking a more holistic approach to needs assessments (as emphasised in the new legislative framework) and developing a more grounded understanding of young carers' lives (for example, through training or by shadowing a young carer for a week).

- **Professionals working in support services should work with young carers in a way which is empowering - helping young carers develop the confidence and ambition to lead a successful independent life**. This includes supporting the development of life skills, life ambitions, effective participation in education, and transition out of established caring roles. Again this is emphasised in the new legislative framework.

- **Raising awareness of dedicated young carers' services among professionals that work with children and families**, so that professionals are in a stronger position to identify and encourage more young carers to seek support.

- **The government and local authorities should continue to fund young carers' projects**. There was recognition that these projects offered valued support to children with caring responsibilities, and an acute awareness among older young carers and parents that local services were under pressure through cuts and reduced budgets.

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Appendix A: Propositions tested with young carers and their families

Explain that we are interested in feedback about what kinds of support, if any, young people who are providing a lot of help at home would find most helpful.

[This part of the interview comes towards the end when children/young people have been given opportunities to talk about their needs as carers and as children and their family needs etc…]

SORTING EXERCISE:

To begin, ask the young person to look through the different 'kinds' of support that might be offered (by local authorities, schools, support providers, etc…) and ask them to think about what they personally would find most beneficial. Lay the cards out and 'rank' them from most to least useful. There are a few examples of the kinds of support which might be offered within a given category on the front of the card; if it is helpful, participants can also see more details on the back of each card to get a sense of the kinds of things that might be involved.

Adapt this exercise as necessary – e.g., older participants may want so sort more independently and privately; those that are having trouble ranking may prefer to roughly sort into piles of 'helpful' and 'not helpful', etc.

CARDS:

(For each the top bullet contains the text for the front of the card; the lower bullets provide examples that would be shown on the back of the card).

Help with money

- Some young people help out managing money or finance and might want advice on how to do this.
- For example, this might include advice on managing household bills, claiming benefits, getting welfare support, or debt advice

Someone to talk to

- Having someone you could chat to in person or on the phone about your life or what worries you.
- Some people just want to be able to talk about their life. Other people might have bad feelings or worries they want to get some help with.
- This could be someone your age, another young person who provides care for someone they love, another local family, someone at school, or a professional like a counsellor. It could be someone new, or maybe even just a friend that you know you can trust.

- Contact could be regular (weekly/monthly) or just there for when you need it.

Support with relationship

- Sometimes it can help to talk through stress that can happen in relationships. This could be your relationship with the person you help out, or with someone else – girlfriends or boyfriends, other friends, other family members.
- There might be advice available about ways to talk through problems or to manage stress.

Information about…

- Sometimes, young people who are helping a loved one cope with illness or other challenges want more information – for example, about what their loved one is going through or what might happen next.
- This could be practical information about mental illness, physical illness and drugs and alcohol, about ways to talk about the kinds of things your loved one is going through, and about planning for the future.
- This could be information you read, or someone to speak to.

Help to stop caring or take breaks

- Lots of young people who help out a lot at home are happy to do so, but others wish they didn't have to. There might be support to stop or do less if you want or take a break from caring.
- Someone could come to talk to your family about how people get supported in your home, and look at ways to provide extra support in caring for your family.
- There might be activities or groups you could attend to allow you a break from caring.

Help to make caring easier

- Sometimes there are practical things – like having new equipment or some extra help from a professional – which could make caring easier. Or maybe you just want more information about how to support the person you are helping out.
- Organisations can help out by providing equipment (like help someone get around the house, chair lifts, or other stuff)
- Arrange for someone to come to your home and help once in a while. For example, sometimes people need help getting someone around the house or lifting them, or help cleaning, cooking and taking care of the house.
- You may want to someone else you know to help you (like family, friends and neighbours) to be there as someone to talk to

Support at school

- Some young people find that the help they provide at home, can make it more difficult to do their school work, attend school or take part in other activities at school
- Sometimes school teachers or support staff can provide extra help with homework or run after school clubs
- You may want to talk to someone at school who understands what it is like to live with a relative who needs their support
- Schools may talk to you about what it will be like when you move on to secondary school or further and higher education

Thinking about the future

- You might want someone to talk to about what you're going to do when you get older – where you might want to work, or whether you'd like to go to University.
- This could include:
  - careers guidance to help you think through different options,
  - help thinking about whether university is right for you,
  - advice on other education options and vocational programmes,
  - help filling out applications for work or education, or
  - support to think about how your family could be supported if you leave home.

Social life

- The chance to get out of the house with other people my age – maybe even with other people who provide care for someone they love
- Support for you to get away to do social activities for an hour or two – or even for longer. For example - school clubs or a place to go chat and hang out, going on trips, or even getting away overnight with other people your age.
- While you are gone, support might be provided for your family so your loved ones still have what they need while you are away.

More information on caring

- Some people want to know more about other young people who help support someone they love.
- There is a lot of information available out there. You could learn more websites, online discussions with other carers, talking to organisations who work with a lot of young carers, reading books, Twitter and Facebook, apps, DVDs… almost any way you want.

I would want…

- (Blank Card for carers to self-complete if they wish)

FURTHER DISCUSSION:

- As appropriate, once areas of support have been sorted, talk through the areas which the young person found most and least attractive. Probe to explore:
  - Why this area would be beneficial for them
  - What makes it attractive – a specific kind of support? A specific kind of need?
  - Who would you like to deliver this – whether informal (friends, family, neighbours) or other organisations (e.g. groups that support young people who care, local council, youth clubs, school etc.)
  - How they would ideally want this to be delivered, as appropriate to the intervention (e.g., in-home/out-of home, ad hoc versus ongoing, format, channels).
  - Whether they would want dedicated support (e.g. just for themselves) or support for the whole family support.
  - Whether support should focus on the care they provide as a child/young person or wider needs as a child/young person
  - If they have used this kind of support, what went well/less well?

Appendix B: Topic guides and stimulus

DfE Young Carers Research
Topic Guide - Family Visits

Overall Aims are to:

1) Help gather up-to-date evidence on the young carers landscape – in terms of barriers to identification, understanding of their/their families' needs, and current support responses, including needs assessments.

2) Explore responses to potential support propositions in order to help inform Local Authority planning in meeting obligations to support young carers and their families under the the Care Act 2014 and the Children and Families Act 2014.

Over the course of the family visit, the researcher will aim to:

-Explore the whole family **experience** of the young person's family support/care-giving and percieved support needs for both carer and wider family

-Explore the **impact** of care-giving on: social activity; health; emotional wellbeing and mental health; education; family dynamics; and general life planning – via general discussion and conduct of elements of the **MACA-YC18 and PANOC-YC20**

-Understand **experiences of needs assessments** to identify support needs, where these have taken place; what has worked well and less well

-Understand **whether and how families/carers have identified to support services** (statutory or third-sector) – identifying motivators and barriers, and what has worked well or less well

-Map the kinds of **support the family is currently receiving** to identify potential gaps and needs; what has worked well and less well

-Explore young carers' views of **support propositions** in terms of how they would meet the needs of young carers and the expected impact on carers and families

-Explore young carers' **expectations and hopes** for the future to explore the longer term impacts of caring on children and young people's aspirations

Key principles for researchers to follow throughout the visit:

- The researcher will not assume any understanding of or idenitifcation with the 'young carer' label; rather, interviews will be framed as 'understanding how families work together to care for each other', focused particularly on the role of children in the home

- Questioning and probing will be framed to ensure we understand young carers'/families' situations as they view them, rather than promoting identification with the young carer label

- Researchers will adapt the approach, as much as possible, to understand the whole family dynamic and role of young caring within this. The particpants involved may vary and will be dependent on who has the caring need. This may be the parent, but could also be a sibling/other family member/outside of home/close non-family member. Likewise – it may be that there is a 'primary' carer but also other siblings involved in caring. The researcher will adapt the questioning as necessary.

- Approaches to using the guide will be flexible and adapted to each family to minimise burden e.g. the order/elements used/how much time is spent in home. There may also be elements of informal observation of interaction within the home – researchers will make notes of observations straight after the visit, capturing any key dynamics or themes related to the research aims and objectives. There will also be flexiblity to conduct the visit in the home only or accompany out of home.

- The researcher will ensure that they observe both non verbal and verbal withdrawal of consent e.g, if someone wants to take a break, is unconfortbable with the line of questionioning, or would like to withdraw.

- If someone becomes upset within the interview, the researcher will check if they want a break or to carry on with partipation in the research visits. All partipants will be left with support materials. We will then notify DfE of any incidents (without naming names).

Our approach to duty of disclosure for this project: TNS BMRB will not disclose family situations (to any organisation e.g. local authority) simply because there is a care situation, regardless of the level of care provided by the young person. This includes situations in which there are negative impacts on the carer due to their family obligations. However we WILL disclose in the case of suspected current or likely risk of harm to participants and others (e.g., suicidality; life-threatening self-harm; and physical abuse/ neglect).

A. General Introduction to the visit (20–30mins)

First introductions to the research will typically be achieved by a family discussion, to help establish rapport with all relevant family members. However, some parents/guardians may want to discuss this separately without other members of the family present. The researcher will ensure that information is covered with ALL family members (this may mean going through the information twice with parents/guardians)

The researcher to read out the following information, and tailor where necessary:

- **The researcher will introduce self** and TNS BMRB, an independent research agency, carrying out research with Loughborough University on behalf of DfE.

- **The researcher will explain that the purpose of research** is to understand how families work together to care for each other, focusing particularly on the role of children in the home and also to give children and young people the opportunity to feedback on the types of support which could potentially help them. We are talking to different families across England (22 in total) to understand their views and experiences.

- **The researcher will discuss TNS BMRB confidentiality and duty of disclosure:**

  - Taking part in the research is both anonymous and confidential – this means we will not be informing any support agencies you work with or the local authority of anything you discuss during our visit or of your current family caring situation. There are no wrong or right answers – we are interested to hear and learn from your experience.

  - We will draw together key themes and issues that families discuss in a report but we will not say who has said what, or put any names in the reports. It will not be possible for anyone outside the research team to know what you personally have told us.

  - **However, if we see or hear something which causes concern about your physical safety, we would have a duty to act to make sure you were protected;** for example, if you tell us something which may cause significant harm to you or another person. If this was to happen, we would talk to you about what to do first – e.g., we would encourage you to talk to someone who can help, or agree that we would talk to support agencies (e.g. local authorities) on your behalf.

- **The researcher will explain recording procedures**: If it is okay with you I would like to record some of our conversations today, so I can concentrate on what you are saying and because it's more accurate than taking notes. The researchers and the person who types up our conversation (as a transcript for our analysis) are the only people who will listen to this.

- **The researcher will explain that we can move on, stop or withdraw at any time:** Taking part is completely voluntary and your choice – if there is a question you don't want to answer that's fine, we can skip it. We can also stop at any time, or just take a break. You can either tell me or just put up your hand if you want to stop or move on to the next question. You can withdraw from taking part at any time.

- **The researcher will ask them if they are happy to continue, and provide written consent to take part. They will then ascertain if participants understand what this means.**

- **The researcher will explain the thank you payment:** You will receive a £40 thank you payment for your time and contribution to the research.

- **The researcher will discuss next steps after the interview:** After we write the report, we will send a summary of what we found to everyone who takes part. We will also be showing our findings from the interviews to other young people to understand further experiences of how families care for each other.

B. Exploring the family dynamic (15-25mins)

Aim: To build rapport, and to understand the circumstances of care-giving and support needs from the whole family perspective.

- **General discussion of family dynamics and interests of different family members (5 -10 minutes)**
    - Who currently lives in the family home? – parents/guardians, brothers/sisters, grandparents, other family members/individuals
    - How long have they been living in the area? - views on the local area
    - *Ask them to talk through the relationships with the family*; what is each person's role within the family?
        - What does each family member do;
        - How does this vary by week and weekend
    - How do they usually spend time together as a family? What activities or hobbies do they do together or separately? *PROBE - activities inside and outside the home*

- **Caring needs and arrangements within the home (5 -15 minutes)**
    - How do they support and help each other as a family; describe the role that each family member has in supporting each other

The following questions to only be asked of families where the young person has been recruited via Young Carers support services or the care need has been explicitly discussed:

- Who within the family requires support?
    - Which family member
    - What is the nature of their care need (e.g. description of the health problem, disability or condition)
    - How long have they needed care for

- How do they talk about the illness/disability/condition (*use language of the family*) within the family?
    - What do they talk about
    - How often do they talk about this

- What kind of support/care is needed for relative with the care need?
- *SPONTANEOUS, PROMPT only where required. (To be covered in further detail in later interviews*)

    - Help with domestic tasks
    - Help with managing the household (financial; time planning; service arrangements, etc.)
    - Personal care
    - Emotional care
    - Helping with looking after other family members (e.g., brothers and sisters or others)
    - Help liaising with support services (e.g., statutory support for illness/disability; councils/LAs; etc.)
    - Other
- For each type of care discussed, explore whose role this is and whether it is shared with other family members

Explain that we are now going to talk in more detail to parent/guardian/sibling and child about their experience of providing care within the household or outside the family home where there are caring arrangements for other relatives/close family friends

C.Parent/guardian/sibling follow up interview (50-60mins)

Aim: to build on family interview and further understand the relationship of care within the family home, the nature of the care issue and parenting support needs

The researcher to only conduct interview if in touch with support agencies/organisations or the care need has been explicitly discussed.

1. **Exploration of parenting/other family member support needs (10-15 minutes)**

The researcher to explain that we want to talk to them in more detail about the care needs in the home and how this first came about

- *(If not already discussed in detail)* What is their current care need? (e.g. illness, disability, condition)

- When was their care need (e.g. illness, disability, condition) first assessed or diagnosed by a Doctor or other health professional?

- What did the diagnosis process involve/how were they assessed?

- Did they receive an assessment of how the illness/disability would impact on other areas of their life?
    - Social
    - Emotional
    - Work
    - Home life
    - Parenting

- What were their views on the outcome of that assessment?

- What support are they receiving to help with their care need (disability/illness/condition)?

- *PROBE*
    - Support to manage the condition
    - Support with parenting
    - Other support to help other areas of their life

- Views on the quality of the support they are currently receiving; what works well and less well?

2. **Impact of care needs on family (10 minutes)**

- How would they describe their relationship with the child? How has this evolved over time?

- How have they discussed the disability/illness with the child?
    - What do they talk about?
    - Any things that have made this discussion easier or harder?

- What impact has the disability/illness had on how the family work together and care for each other?
    - Impact on types of tasks/activities and how shared within the family
    - The specific role of the child and level of responsibility

- What impact has the child's caring role had on other areas of the child's life?

- What do they think are the benefits of the responsibility the child has taken on? Are there any down-sides? *(Researcher to assess spontaneous responses, listening out for the categories below, and sensitively probing as necessary)*
    - Having fun/socialising
    - How happy/sad they feel
    - Going to school/school achievement/performance
    - Health/how healthy they feel
    - Future plans/aspirations

- **Assessment of caring needs within the home (10-15 minutes)**

    - What (if any) services/support agencies have been in contact or talked to them about how the child or other family members provide care in the home?
        - What led to this contact being made; whether initiated by child, family or others?
        - How did they feel about this at the time?

    - If the family have not disclosed the child's caring responsibilities; have they considered approaching any support services or professionals for help, and why/why not?
        - Potential barriers/potential benefits

- *PROBE*

  - Impact of involvement of LA/social services

  - Impact on the family and relationships

  - Impact on care need and health issue

  - Other

  - What would make this easier?

- *Spontaneous and then PROBE*

  - Level of control/choice on whether they have contact with the service/professionals

  - Other guarantees/promises made by service/professionals on what will happen next

  - Other

- If the family has disclosed – how/why?

  - What led to this?

  - Any barriers?

- Has any of the support services/organisations carried out assessments to identify the type of needs the child or other family members have in providing care? (this usually involves a list of questions to see what happens in the home and the kind of needs the child or the family have)

  - What was nature of the assessment, what did this involve for the family and child?

  - Who conducted the assessments?

  - What happened after the assessment, did it lead to any actions/outcomes?

  - Views on how well the assessment identified needs

  - What happened after; whether this led to support or actions that met their needs?

- **Views on support accessed by young carer (10 minutes)**

  - What support (if any) does the child or other family members receive in relation to their caring role? (e.g. more formal support outside the home by organisations/agencies or friends/families)

  - *PROBE*

- Health care services

- Social care support

- School/other education services

- Voluntary or charitable services.

- Support services/groups

- Support networks/forums

- Informal support from friends

- Support from family

- Support from neighbours

- Parenting support

- Other

- *For each support discussed,* what does this involve?

    - At what point were services provided (ask them to think about the time or age of child)?

    - Who delivers this?

    - The nature of the support; what does it involve?

    - How often is support provided?

- How useful has the support offered been?

    - What has worked well and what has worked less well about the support provided?

    - Barriers to take-up

    - Outstanding gaps and any impact of these

- **Suggestions/improvements to support options (10 minutes)**

    - What would they suggest would further help and support their family and the child? – *Then discuss the support propositions as prompts*

- *Explain that we are interested in feedback about what kinds of support, if any, young people who are providing a lot of help at home would find most helpful.*

    Ask the participant to look through the different 'kinds' of support that might be offered (by local authorities, schools, support providers, etc…) and ask them to think about what they personally think would be most beneficial to the young carer and family.

CARDS:

(For each the top bullet contains the text for the front of the card; the lower bullets provide examples that would be shown on the back of the card).

- **Talk through the areas which are highlighted as helpful.** PROBE to explore:

    - Why this area would be beneficial for the young carer and family

    - What makes it attractive – a specific kind of support? A specific kind of need?

    - Who would be best to deliver this – whether informal (friends, family, neighbours) or other organisations (e.g. groups that support young people who care, local council, youth clubs, school etc.)

    - How would this be ideally delivered (e.g., in-home/out-of home, ad hoc versus ongoing, format, channels).

    - If they/young person have used this kind of support, what went well/less well?

- What would best help the child achieve their ambitions/hopes for the future?

- What would an ideal world scenario look like for the child?

D.Private, semi-structured interviews with carers (45-75 mins)

Aim: to explore their current experience of care-giving and perceived support needs. Researchers to build on family discussions with tailored prompts and probing – exploring the circumstances and issues raised through the carers' own perspective.

Each interview will be tailored in length and content dependent on the individual child. The activity options will be used where required, and in particular for younger children aged 5-11.

2. **Understanding of their current responsibilities in the home (10 - 15 minutes)**

The researcher to ask the young person to provide a guided walk through the house, to explore what a typical day looks like to them

- What kind of things they do in each room on a typical day? – *explore both weekday and weekend*

- What do they enjoy/not enjoy in the activities highlighted?

- What does a regular day look like outside of the home?

  - Attending school

  - After school activities/homework

  - Social life and friends

  - Hobbies/activities they enjoy

The researcher to focus on the current activities, where the young person provides care for the family within the house

- *PROMPT with activities previously discussed*, what do these activities involve?

- How much time do they roughly spend on activities in a day; how does that then work across a week?

- Do they do this on their own/shared with other members of the family?

- How do they feel when carrying out these activities; what do they enjoy/dislike?

- Do the care activities discussed change at all (*get them to think about the last month, or further back*)? - *PROBE* length, their involvement; how they feel about them

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Activity A [tool to facilitate discussion if necessary]

Day in the life drawings, where the young person is asked to draw how they think young people help out in home

- What do they like/dislike about their activities, and why

- How does this compare with what they regularly do, and why

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*Explain that we are now going to look at in more detail the types of tasks they do at home, and ask them to complete the **MACA – YC18***

3. **Discussion of young carers' current experiences/needs and perceived impact of caring (5 -10 minutes)**

- *(If care need not already explicitly discussed)* Does any relative/or close family friend have a health need (illness, disability, condition)?

- How did they feel when they first found out about their relative's care need (e.g. health need– illness, disability, condition)?

    - Have they talked to their relative about their health need (e.g. illness, disability, condition); if not why?

    - How did the parent/relative discuss this with them?

- Has anyone from health, social care services or other organisation talked to them about their relative's illness or disability and how it affects them and their family?

    - What did that involve?

    - Did this involve an assessment (e.g. a list of questions to understand their needs)

    - How useful was this discussion?

    - What happened after the discussion?

    - If not, would they find it useful to talk to an organisation

- What kind of impact/difference did their relative's illness or disability have?

- PROBE both positives and negatives

    - Relationship with parent/relative

    - Relationship with siblings and other family members

    - The role within the house e.g. providing practical help in house because of their relative's health need (such as cooking, cleaning, helping with household chores)

    - Providing help with their relative's health need e.g. medical/nursing help (such as helping to wash or dress them, give medication, helping them move)

4. **Views on the impact of caring role (10 minutes)**

- *Ask them to think back to when they started to help with care* (months/years); How old were they at the time?

- What do they enjoy/dislike about the care they provide in the home?

- How does carrying out these tasks make them feel?

  - About themselves

  - About their family

Activity B [tool to facilitate discussion if necessary]

To use a blob drawing showing visually different emotions

Activity C [tool to facilitate discussion if necessary]

To draw or use/select words to describe this

- How much time do they have to spend on other activities/having time for themselves? *FOCUS on areas previously discussed, but PROMPT if necessary*

  - Socialising/spending time with friends

  - Attending school

  - Attending after school activities/hobbies

  - Carrying out homework

  - Other

- How do they feel about the amount of time they get to spend on these activities?

  - How much does this feel the right amount/not the right amount of time?

- What difference does the care they provide make to other areas of their life?

    - Having fun/socialising

    - How happy/sad they feel

    - Going to school/school achievement/performance

    - Health/how healthy they feel

    - Planning for the future

    - Relationships with family members

- *(Where appropriate e.g. where the researcher feels that further discussion is required) introduce the **PANOC – YC20** and that we now want to look at some things young carers have said about what it feels like to look after someone*.

-

5. Assessment and identification of needs as a young carer (5 -10 minutes)

- Have any services/support agencies been in contact or talked to them about how they provide care in the home?

- What led to this contact being made; whether initiated by the child, family or others?

    - How did they feel about this at the time?

    - What was easy/hard about this?

- (If no contact with support services/professional), Why they haven't discussed their needs with other services/professionals or other people they know outside the family?

    - How would they feel about talking to a support service/professional?

    - What are their expectations of what would happen if they were to contact or talk to a support service/professional?

- Have any support services/organisations carried out assessments to identify the type of needs they have because they provide care in the home (this usually involves a list of questions to see what happens in the home and the kind of needs they have as a family)

    - What was nature of the assessment, what did it involve?

    - Who conducted the assessments?

- What happened after the assessment? Did it lead to any actions/outcomes?
  - Views on how well the assessment identified their needs
  - Whether this led to support or actions that met their needs?

6. **Experiences of receiving support for themselves as carers and for themselves as children who live in a family affected by illness/disability (5- 15 minutes)**

- What support (if any) do they receive **to help support caring needs in the home?** (e.g. more formal support outside the home by organisations/agencies or friends/families)
  - Health care services
  - Social care support
  - School/other education services
  - Voluntary or charitable services.
  - Support services/groups
  - Support networks/forums
  - Informal support from friends
  - Support from family
  - Support from neighbours

- For support previously discussed, what did this involve?
  - How did they first come in contact?
  - Did someone at the organisation talk to them about their specific needs?
  - How comfortable did they feel talking about their needs and what was happening at home?
  - What kind of activities/things has this involved?
  - How helpful have they found the support?
  - What has worked well and what has worked less well about the support provided?
  - What difference has it made for them?

  -

- What support (if any) do they receive to support them as a child **who lives in a family affected by illness/disability?** (e.g. more formal support outside the home by organisations/agencies or friends/families)
    - Health care services
    - Social care support
    - School/other education services
    - Voluntary or charitable services
    - Support services/groups
    - Support networks/forums
    - Informal support from friends
    - Support from family
    - Support from neighbours
  -

- For support previously discussed, what did this involve?
    - How did they first come in contact?
    - Did someone at the organisation talk to them about their specific needs?
    - How comfortable did they feel talking about their needs and what was happening at home?
    - What kind of activities/things has this involved?
    - How helpful have they found the support?
    - What has worked well and what has worked less well about the support provided?
    - What difference has it made for them?
    - What (if any) additional help/support would they like or need?

7. **Views on the usefulness and impact of support propositions (15 minutes)**

- *Explain that we are interested in feedback about what kinds of support, if any, young people who are providing a lot of help at home would find most helpful.*

SORTING EXERCISE:

To begin, ask the young person to look through the different 'kinds' of support that might be offered (by local authorities, schools, support providers, etc…) and ask them

to think about what they personally would find most beneficial. Lay the cards out and 'rank' them from most to least useful. There are a few examples of the kinds of support which might be offered within a given category on the front of the card; if it is helpful, participants can also see more details on the back of each card to get a sense of the kinds of things that might be involved.

Adapt this exercise as necessary – e.g., older participants may want so sort more independently and privately; those that are having trouble ranking may prefer to roughly sort into piles of 'helpful' and 'not helpful', etc.

CARDS:

(For each the top bullet contains the text for the front of the card; the lower bullets provide examples that would be shown on the back of the card).

- **As appropriate,** once areas of support have been sorted, **talk through the areas which the young person found most and least attractive.** PROBE to explore:

  - Why this area would be beneficial for them

  - What makes it attractive – a specific kind of support? A specific kind of need?

  - Who would you like to deliver this – whether informal (friends, family, neighbours) or other organisations (e.g. groups that support young people who care, local council, youth clubs, school etc.)

  - How they would ideally want this to be delivered, as appropriate to the intervention (e.g., in-home/out-of home, ad hoc versus ongoing, format, channels).

  - Whether they would want dedicated support (e.g. just for themselves) or support for the whole family support.

  - Whether support should focus on the care they provide as a child/young person or wider needs as a child/young person

  - If they have used this kind of support, what went well/less well?

8. Wishes and hopes for the future (5 minutes)

- What are their hopes for the future, what would they like to do or achieve?

- *ASK the participant to think about all areas in their life*

  - School/Education/Work

  - Friendships/Relationships

  - Health

  - How they feel about themselves; enjoyment/happiness in life emotional health and well-being

- What current things will help or make it difficult to achieve their future goals?

- What would need to change to achieve this?

- What one piece of advice or feedback would they give to agencies/organisations that aim to support young people in how they help families to work together to care for each other?

- What would an ideal world scenario look like for young people, like them, who help to care for relatives with health issues (e.g. illness, disability, condition)?

Thank and close

- *Leave support leaflet*

- *Snowballing: Explain that we want to talk to other children and young people like them, and if they know anyone who they feel would like to take part that they can contact us*

- *Observations: Note down any informal observations including differences to sample profile and any additional information on whether from BME groups or whether English is an additional language.*

The caring jobs I do

MACA-YC18

Below are some jobs that young carers do to help. Think about the help you have provided **over the last month.** Please read each one and put a tick in the box to show how often you have done each of the jobs in the last month. **Thank you.**

	Never	Some of the time	A lot of the time
1 Clean your own bedroom	☐	☐	☐
2 Clean other rooms	☐	☐	☐
3 Wash up dishes or put dishes in a dishwasher	☐	☐	☐
4 Decorate rooms	☐	☐	☐
5 Take responsibility for shopping for food	☐	☐	☐
6 Help with lifting or carrying heavy things	☐	☐	☐
7 Help with financial matters such as dealing with bills, banking money, collecting benefits	☐	☐	☐
8 Work part time to bring money in	☐	☐	☐
9 Interpret, sign or use another communication system for the person you care for	☐	☐	☐
10 Help the person you care for to dress or undress	☐	☐	☐
11 Help the person you care for to have a wash	☐	☐	☐
12 Help the person you care for to have a bath or shower	☐	☐	☐
13 Keep the person you care for company e.g. sitting with them, reading to them, talking to them	☐	☐	☐
14 Keep an eye on the person you care for to make sure they are alright	☐	☐	☐
15 Take the person you care for out e.g. for a walk or to see friends or relatives	☐	☐	☐
16 Take brothers or sisters to school	☐	☐	☐
17 Look after brothers or sisters whilst another adult is near by	☐	☐	☐
18 Look after brothers or sisters on your own	☐	☐	☐

We care what YOU think

Multidimensional Assessment of Caring Activities-Young Carers (MACA-YC18)

How caring affects me

PANOC-YC20

Below are some things young carers like you have said about what it feels like to look after someone. Please read each statement and tick the box to show how often this is true for you. There are no right or wrong answers. We are just interested in what life is like for you because of caring. **Thank you.**

	Never	Some of the time	A lot of the time
1 Because of caring I feel I am doing something good	☐	☐	☐
2 Because of caring I feel that I am helping	☐	☐	☐
3 Because of caring I feel closer to my family	☐	☐	☐
4 Because of caring I feel good about myself	☐	☐	☐
5 Because of caring I have to do things that make me upset	☐	☐	☐
6 Because of caring I feel stressed	☐	☐	☐
7 Because of caring I feel that I am learning useful things	☐	☐	☐
8 Because of caring my parents are proud of the kind of person I am	☐	☐	☐
9 Because of caring I feel like running away	☐	☐	☐
10 Because of caring I feel very lonely	☐	☐	☐
11 Because of caring I feel like I can't cope	☐	☐	☐
12 Because of caring I can't stop thinking about what I have to do	☐	☐	☐
13 Because of caring I feel so sad I can hardly stand it	☐	☐	☐
14 Because of caring I don't think I matter	☐	☐	☐
15 Because of caring I like who I am	☐	☐	☐
16 Because of caring life doesn't seem worth living	☐	☐	☐
17 Because of caring I have trouble staying awake	☐	☐	☐
18 Because of caring I feel I am better able to cope with problems	☐	☐	☐
19 I feel good about helping	☐	☐	☐
20 Because of caring I feel I am useful	☐	☐	☐

We care what YOU think.

Positive and Negative Outcomes of Caring-Young Carers (PANOC-YC20)

DfE Young Carers Research
Topic Guide – Validation Workshops

Overall Aims are to:

1) Help gather up-to-date evidence on the young carers landscape – in terms of understanding of their/their families' needs, barriers to identification, and current experiences of and needs from support services, including needs assessments.

2) Explore responses to potential support propositions in order to help inform Local Authority planning in meeting obligations to support young carers and their families under the the Care Act 2014 and the Children and Families Act 2014.

Over the course of the peer review workshop, the researcher will aim to:

- Validate and extend findings emerging from the family visits

- Explore young carers' views of **support propositions** in terms of how they would meet the needs of young carers and the expected impact on carers and families

- Explore young carers' **expectations and hopes** for the future to explore the longer term impacts of caring on children and young people's aspirations

Key principles for researchers to follow throughout the workshop:

- The researcher will ensure that they observe both non verbal and verbal withdrawal of consent e.g, if someone wants to take a break, is uncomfortable with the line of questionioning, or would like to withdraw.

- If someone becomes upset within the discussion, the researcher will check if they want a break or to carry on with partipation in the research. All partipants will be left with support materials. We will notify DfE of any incidents (without naming names).

A.General Introduction to the workshop (2 mins)

The researcher to read out the following information, and tailor where necessary:

- **The researcher will introduce self** and TNS BMRB, an independent research agency, carrying out research with Loughborough University on behalf of DfE.

- **The researcher will explain that the purpose of research** is to understand how families work together to care for each other, focusing particularly on the role of

children in the home and also to give children and young people the opportunity to feedback on the types of support which could potentially help them. We are talking to different families across England (22 in total) to understand their views and experiences and today we will share key points that emerged and discuss with you how they resonate with your experience and discuss ways young people can be best supported. We are here to see if what we've heard so far makes sense to you, to check if we've got it right, and to learn more.

- **The researcher will discuss TNS BMRB confidentiality and duty of disclosure:**

  o Taking part is confidential and anonymous – we will not be sharing what will be discussed here with support workers, your families or anyone else.

  o We will draw together key themes and issues that we discuss in a report but we will not say who has said what, or put any names in the reports. It will not be possible for anyone outside the research team to know what you personally have told us.

- **The researcher will explain recording procedures**: If it is okay with you I would like to record our conversations today, so I can concentrate on what you are saying and because it's more accurate than taking notes. It will only be researchers and the person who types up our conversation who will listen to this.

- **The researcher will provide written consent to take part. They will then ascertain if participants understand what this means.**

- **The researcher will explain the thank you payment:** Because all of you have donated your time, we've given a small donation to your young carers' centre so that they can treat everyone. OR You will receive a £20 thank you payment for your time and contribution to the research.

  The researcher will discuss next steps after the interview: After we write the report in early summer, we will send a summary of what we found to everyone who takes part.

B. Introductions (5 mins)

Researcher to ask participants to introduce selves, including age; name one thing they enjoy doing outside the home (hobbies etc.); and say a bit about who they help support or care for.

C. Experience of caring (20mins)

Researcher to explain: *during the first stage of the project, when we talked to 22 young carers, we found that there are certain things they thought were great about caring for a family member and some others that they thought were a bit harder. We'd like to talk some of that through with you.*

Initial validation and general discussion of benefits and challenges of caring (10 min)

*Researcher to introduce findings from family visits for initial validation and spontaneous discussion around priority impacts. Ask the group to look through **STIMULUS A** and for each person to add stickers to the things they think are most important or true for lots of young people who care.*

Wider moderated discussion on impact of caring for young people (10 min)

- What stood out to them most from what we had them look through? What sounds familiar to them?

    - Explore whether / how they identify with statements – which/why
    - Moderator to probe as necessary to understand the extent to which these statements can depend on type of care needs (physical, mental, emotional etc)

- What, if anything, is missing?

- Have we gotten anything wrong? Anything you think isn't true for young carers?

- As necessary, probe both positives and negatives against the below:

    - PROBE both positives and negatives

        - Relationship with parent/relative

        - Relationship with siblings and other family members

        - Future aspirations

        - Social life

        - School performance/attainment

        - Health/how healthy they feel

D. Experience of supports and assessments (25-30 min)

Introducing discussion on impact of caring on carers' lives

Researcher to explain: *One of the things we're interested in is how much help young people and their families get when they are providing support or care to others, and how well that works. We've found it's pretty different person by person – a lot of people aren't really getting help from anyone at all, some young people are getting help from young carers' groups like this, some people have more help from social workers, the council, their schools, and others.*

Blind vote to understand range of support providers (5+ min)

We're going to do a blind vote to talk about the different kinds of support people here might get. I'm going to ask you all to close your eyes, and then I'll read out some different kinds of people who might give support or advice or help out. If you hear one that you get help from, raise your hand.

- Young carers' support groups (NB – do first as a check that everyone understands the task; everyone should raise their hand to this one! ☺)

- Other family members (siblings, aunts and uncles, grandparents, others)

- Family friends and neighbours

- Health care services – e.g., home support for a loved one with physical disabilities, or mental health support

- Social care – e.g., social workers or professionals who come to the home to help out

- Your school or other education groups (like after school clubs, education mentors, a school counsellor or special teacher)

- Charities

- Your church or other religious group

Researcher to feed back summary info from the blind vote to ease discussion. For example: Great – so from my count, it looked like lots of you have spoken to X, get help from XYZ, and some of you are also doing X. A few of you are also doing X. Not very many of you are getting much help from X.

Why do you think that is?

- Why are X the places that people are getting the most help from currently?

- Why are Y the places that people aren't getting much help from in this group?

Experiences of support services (5-10 min)

Researcher to guide general discussion on what young people find most/least useful from support services they use.

- What they value the most/least about the support they are receiving
    - Spontaneous, then probe:
        - Most mentioned in family visit research: a fun break; socialising with people in similar circumstances; understanding how to cope or manage stress; getting guidance and information about what their loved one is going through; practical support and help with tasks to make care easier (e.g. taking care of the house, nursing and financial)
    - Anything else?

- What does the **best support** you got look like
- What was the best **advice** you got about your caring responsibilities
    - Who from
- Who was the best type of person they got support from
    - Why this person (teacher, support worker, family member, other)
    - How did they help
    - How long had they been in contact / knew them
- Anything really NOT work for them?

Concerns about using support services (10 min)

Researcher to further explain: *We are speaking to some young people who aren't really getting any help from anyone at all about all the support and care they provide. In particular, a lot of families aren't in touch with their council, even though councils might be able to provide help. We are curious about your thoughts about why that might be.*

*Researcher to hand out **STIMULUS B** – and have mini-groups spend 5 minutes writing down what people might be concerned about. Then to discuss as a group and probe as necessary:*

- What are the key reasons people may hesitate contacting a support organisation / ask for help / talk to someone about their situation
- What would you say to these people
- What could they learn from your experience

- how would they expect contact could be made
- What would make this easier? *Spontaneous and then PROBE*
  - Level of control/choice on whether they have contact with the service/professionals
  - Other guarantees/promises made by service/professionals on what will happen next
  - Other

Experiences of and views on assessments (5-10 min)

Researcher to introduce discussion: *Sometimes it can be useful to talk to someone and give them a good idea of everything you do for your family member or loved one, talk about what you find difficult, and think about all the help that could be provided. Instead of arranging a bit of support here or a bit of support there, this kind of assessment might be useful to take a big-picture view of what you or your family might find useful.*

We are curious if anyone here has had that kind of chat and how well it went.

To probe as below:

- Have any of the support services/organisations carried out assessments to identify the type of needs you or other family members have in providing care? (this usually involves a list of questions to see what happens in the home and the kind of needs the child or the family have)
  - What was nature of the assessment / what did it involve
    - For child
    - For person cared for (if applicable)
    - For family as a whole (if applicable)
  - How did they feel about this at the time – any concerns?
  - What was discussed during assessment – who with
- If this has helped them – in what ways
- Anything really not work?
- Thoughts about being identified as a young carer – what they like/don't like about it?

Researcher to further explain: *In the future, this kind of assessment might be more common – Local Authorities, or councils, would talk through what you and your family need to help decide what kind of support can be offered.*

- Do they think families and young people will find this helpful?

- Would they have any concerns or hesitations?

- How might these be overcome?

E.Prioritising support (25 mins)

Researcher to explain: We've talked about a lot of kinds of support that young people might benefit from. In the future, hopefully young people will get more support. Now we want to think with you about what might be the priority support to offer:

Sorting exercise:

*To begin, ask the young people to look through the different 'kinds' of support that might be offered (by local authorities, schools, support providers, etc…) (**Stimulus C – support propositions**) and ask them to think about what they personally would find most beneficial.*

Then split the group into two mini groups. Give each mini-group stickers. They will then

Read out each support type and have people raise their hand if they think something is useful – and put on one sticker per person. Then to quickly lay them all out on the table in the order of most to least useful (most to least stickers).

There are a few examples of the kinds of support which might be offered within a given category on the front of the card; if it is helpful, participants can also see more details on the back of each card to get a sense of the kinds of things that might be involved.

Sorting card discussion

As appropriate, once areas of support have been sorted, talk through the areas which the group found most and least attractive. PROBE to explore:

- Why this area would be beneficial for them

- What makes it attractive – a specific kind of support? A specific kind of need?

- Who would you like to deliver this – whether informal (friends, family, neighbours) or other organisations (e.g. groups that support young people who care, local council, youth clubs, school etc.)

- How they would ideally want this to be delivered, as appropriate to the intervention (e.g., in-home/out-of home, ad hoc versus ongoing, format, channels).

- Whether they would want dedicated support (e.g. just for themselves) or support for the whole family support.

- Whether support should focus on the care they provide as a child/young person or wider needs as a child/young person

- If they have used this kind of support, what went well/less well?

F. Looking forward (5 mins)

Wishes and hopes for the future

- What are their hopes for the future, what would they like to do or achieve?

- *Ask participants to think about all areas in their life*

    - School/Education/Work

    - Friendships/Relationships

    - Health

    - How they feel about themselves; enjoyment/happiness in life emotional health and well-being

- whether future plans/aspirations have changed over time – why/why not

- What current things will help or make it difficult to achieve their future goals?

- What would need to change to achieve this?

- What would an ideal world scenario look like for young people, like them, who help to care for relatives with health issues (e.g. illness, disability, condition)?

G. Summing up (5-10 mins)

- What would you say to the people that make decisions about providing support to young carers? *[STIMULUS D]*

- *Ask them to write on small piece of paper and then put on big card . Then PROBE*:

- Why do they think this message is important

- Who would this kind support be more/less suitable for

- Who should be providing this support

- Any final thoughts/comments

Thank and close

Appendix C: Research ethics

The following key ethical considerations where used to guide the design and conduct of the study, including drawing on the guidance and expertise of Professor Jo Aldridge in the ethics of conducting this type of research.

Research methods used

- Topic guides and research tools were designed to ensure appropriateness and flexibility in terms of children's age and level of maturity. Age appropriate stimulus materials and activities were used to facilitate discussion with children who may find more structured 'interviewing' intimidating or disengaging. (e.g. open ended questions and visual tools/approaches to enable discussion).
- All topic guides and stimulus materials were developed with the input of the Advisory Board and Professor Jo Aldridge.

Obtaining informed consent

- TNS BMRB followed best practice developed by the National Children's Bureau and Barnardo's[8] to ensure that young people are fully involved in the consent process.
- Researchers obtained dual consent from both the parent/guardian and child/ren. To ensure that respondents were informed at the point of giving consent, they were given written and verbal information about what they would be asked to do, and what will happen to the information they gave, in order to make an informed decision regarding participation.
- Age-appropriate information was provided in a clear and accessible written form. Children had the opportunity to ask questions about the research, should they wish.
- Written consent was obtained (voluntary and fully informed) from all participants, including young carers but also other family members.

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[8] National Children's Bureau: Guidelines for Research (2003), and Barnardo's Statement of Ethical Research Practice (www.barnados.org.uk/resources)

Confidentiality and disclosure of harm

- The confidentiality of information supplied by research subjects and the anonymity of respondents was respected. TNS BMRB followed ethic guidelines if there were exceptional situations which overrided a duty of confidence to the research participant, for example:
    - Where there was an legal requirement (either under statute or a court order) to disclose the information (for instance, notification of certain diseases to public health authorities)
    - Where there was an an overriding duty to the public (for instance, the information concerns the commission of a criminal offence or the safety or wellbeing of the respondent or someone in the household), or
    - Where the individual to whom the information relates had consented to the disclosure

- In addition TNS BMRB had a specfic approach to duty of disclosure as follows: TNS BMRB did not disclose family situations (to any organisation e.g. local authority) where there was a care situation, regardless of the level of care provided by the young person. This included situations in which there were negative impacts on the carer due to their family obligations. However TNS BMRB would disclose any suspected current or likely risk of harm to participants and others (e.g., suicidality; life-threatening self-harm; and physical abuse/ neglect). Any disclosures or observations would then be reviewed by the Project Director.

The conduct of interviews

- All researchers had valid Disclosure and Barring Service (DBS) checks to conduct research with children.
- All researchers provided full reassurance of independence and confidentiality, as well as clarity regarding duty of disclosure.
- The researcher did not assume understanding of or idenitifcation with the 'young carer' label in interviews. Interviews were framed as 'understanding how families work together to care for each other', focused particularly on the role of children in the home.

- Questioning and probing was framed to ensure researchers understood young carers'/families' situations as they view them, rather than promoting identification with the young carer label.
- Approaches to using the guide were flexible and adapted to each family to minimise burden e.g. the order/elements used/how much time is spent in home.
- Families and child/ren were also given the flexiblity to conduct the visit in the home only or out of home.
- The researcher ensured that they observed both non verbal and verbal withdrawal of consent e.g, if someone wanted to take a break, was unconfortbable with the line of questionioning, or would like to withdraw.
- If someone became upset within the interview, the researcher checked if they wanted a break or to carry on with partipation in the research visit.

Providing respondents with information on where to get support

- All partipants were left with support materials of national support and advoacy organisations for children and young carers.

Data management

- All data from young carers and their families was kept anonymously and confidentially. All interviews were recorded using fully encrypted audio recorders, with written consent taken for recording being taken prior to fieldwork.

Validation of findings

- In order to validate and further explore the research findings a peer review workshop was conducted with young people (n 9) aged 11-17 who attended young carer projects. The findings from the primary stage of the research were shared and discussed to validate key findings on the types of support local authorities should prioritise.

Providing feedback to participants about the findings from the study

- Summaries of the findings were shared with carers and families who took part in the research.

Information letter for parents/guardians

Who are we?

We are researchers from TNS BMRB, an independent research organisation which carries out research about services for members of the public. We don't work for the local authority, or any other support service or organisation. The Department for Education has commissioned us to undertake research to explore how children, young people and their families work together to support each other when care needs to be provided to a family member/guardian.

What do we want to know?

We have been asked to find out how you and your family work together to look after each other. We are talking to different types of families across England to understand their views and experiences. The research will focus on the role children and young people play in the household and the types of support families might need. The research aims to enhance existing knowledge and understanding about young people and their families' needs and help inform future planning and policy.

What will happen?

We would like to visit you at home or another neutral space for 3-4 hours to discuss how you work together to care for each other in your family. This will involve interviews with you as a family, and separate interviews with you and your child. You will not have to prepare in advance, and the visit will happen at a time that is convenient to you. **You won't have to talk about anything you don't want to** and with your permission we would like to record our conversation so we can pay attention to what you are saying and to have an accurate record of our conversation. If you are willing to take part, your family will receive a **thank you payment of £40** as our way of appreciating the time you have given to take part in the research.

Will it be private?

Yes, everything you tell us will be private and **anonymous**. Only the researcher and the person who types up the notes will listen to the conversation. We will then put what everyone says together in a report but we will not say who has said what, or put any names in reports. When our visits are complete, we will send you and your family a summary of the findings so you can see what other families' experiences and potential support needs are.

We will not be informing any support agency of your family situation, however if you tell us something that causes significant harm to you or another person, we would talk to you first about what to do or agree that we would talk to support agencies on your behalf.

Can I change my mind about talking part?

Yes, at any time. If there is any question you don't want to answer that is fine. Also you can stop the interview at any time.

If you have any questions or things you're not sure of contact Naomi Day at Naomi.day@tns-bmrb.co.uk or on 020 7656 5741 or Jessica Dunn at Jessica.DUNN@education.gsi.gov.uk or 0114 2742242 (Monday-Wednesday).

Information letter for children

Who are we?

We are researchers from TNS BMRB, an independent research organisation which carries out research about services for members of the public. We don't work for the local authority, or any other support service or organisation.

What do we want to know?

We are talking to children, young people and their families on behalf of the government's Department for Education to find out how you and your family work together to care and look after each other. We are talking to different types of families across England to understand the role children and young people have in the household and the types of support families may need.

What will happen?

We would like to visit you at home or another place you feel comfortable in for 3-4 hours to understand how you and your family care for each other. This will involve interviews with members of your family, and a separate interview with you. This will happen at a time that is convenient to you and **you won't have to talk about anything you don't want to**. You will not have to prepare anything, and if it is okay with you we would like to record our conversation so we can pay attention to what you are saying. It is also more accurate than taking notes. If you and your family are willing to take part, your family will receive a **payment of £40 as a thank you** for your time and contribution to the research.

Will it be private?

Yes, everything you tell us will be private and will not share your name with anyone else. Only the researcher and the person who types up the notes will listen to the conversation. We will put what everyone says together in a report but we will not say who has said what, or put any names in reports. When our visits are complete, we will send you and your family a summary of what we find out so you can see what other families' views and experiences are.

Please know that if we see something that causes concerns about your health and safety, we would first talk to you and your family about what to do or agree that we would talk to support agencies for you.

Can I change my mind about talking part?

Yes, at any time. If there is any question or topic you don't want to talk about that is fine. Also you can stop the interview at any time.

If you have any questions or things you're not sure of contact Naomi day at Naomi.day@tns-bmrb.co.uk or on 020 7656 5741.

Written consent form

Consent to take part in the research

We are talking to children, young people and their families on behalf of the government's Department for Education to understand how they work together to look after each other and the role children and young people have in the home. What you tell us will be used to help design support that will help children and families in the future.

Yes	No	
☐	☐	I understand what the research is about and that I am being asked to answer questions about the way my family care for each other
☐	☐	I give permission to record what I say so the researchers have an accurate record of our conversation
☐	☐	I understand that my details will not be shared with anyone and that my name will not be used in any research reports
☐	☐	I understand that I do not have to take part.
☐	☐	I understand that I can refuse to answer any question or to stop taking part at any time.

Your name...

Signature...

If under 16 – named adult with permission to additionally consent for the young person:

- I have read the information sheet and consent details (above) provided for children and young people
- I am happy for the above young person **to be asked to take part** in an interview for this research

Your name...

Role and relationship to young person ……………………………………

Support information

How families care for each other

Need some help?

If you feel you want to talk to someone to get **support, advice or information**, you might want to contact one of the organisations specialising in providing services to children and families below.

- **Carers Trust**
  www.carers.org and www.youngcarers.net

  0844 800 4361

- **The Children's Society**
  www.childrenssociety.org.uk

  0300 303 7000

- **Barnardos**
  www.barnardos.org.uk

- **NSPCC**
  www.nspcc.org.uk

  0800 1111

- **Childline**
  www.childline.org.uk

  0800 1111

This research was commissioned under the 2010 to 2015 Conservative and Liberal Democrat coalition government. As a result the content may not reflect current Government policy. The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.

Any enquiries regarding this publication should be sent to us at: gail.peachey@education.gsi.gov.uk or www.education.gov.uk/contactus

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